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Symptoms of posttraumatic stress disorder in young males diagnosed with testicular or lymphatic cancer

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Symptoms of posttraumatic stress disorder in young males diagnosed with testicular or lymphatic cancer

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RÉSUMÉ

Les cancers testiculaires et lymphatiques (maladie de Hodgkin's et Non-Hodgkin's) sont parmi les cancers les plus répandus chez les jeunes hommes âgés de 18 à 45 ans. Ce n'est que récemment que le cancer fut considéré comme un événement suffisamment stressant pour répondre aux critères diagnostics du Trouble de Stress Post-traumatique (TSPT) avec des taux d'incidence variant entre 1.9 et 35.1% (Kangas, Henry & Bryant, 2002). Ce projet en deux volets a pour but d'explorer les symptômes de TSPT et de détresse reliés au cancer, de déterminer la fréquence des symptômes de TSPT chez les jeunes hommes atteints de cancer, d'établir une trajectoire développementale des symptômes de TSPT dans la première année suivant le diagnostic de cancer, d'identifier les facteurs de risque qui prédisent les symptômes de TSPT et de décrire les moyens de coping et de croissance post-traumatique des survivants. Dans la première étude, 22 survivants de cancer testiculaire ou lymphatique ont participés à une entrevue semi-structurée de façon rétrospective. Le verbatim de ces entrevues fut analysé selon la méthode d'analyse qualitative de Miles et Huberman (1984). La période du diagnostic fut vécue comme un choc et une menace s'accompagnant souvent d'anticipation anxieuse, de déni ou d'évitement. Les réactions les plus communes lors de la période des traitements étaient le désespoir et le découragement. À long-terme dans la période post-traitement, certains firent l'expérience d'une réaction émotionnelle retardée et les symptômes de TSPT (présence accrue d'intrusions et d'évitement) devinrent plus courants. L'optimisme était la méthode de coping précoce la plus commune et plusieurs rapportèrent une croissance post-traumatique dans la période de survie à long-terme. Les résultats de cette étude sont conformes au modèle socio-cognitif transitionnel d'ajustement (social-cognitive transition model of adjustment) (Brennan, 2001). Dans la seconde étude, des patients

nouvellement diagnostiqués avec le cancer (n=92) et des volontaires de la communauté (n=88) ont été recrutés et suivis prospectivement pour une période de 12 mois. Des niveaux symptomatiques sévères de TSPT furent observés chez jusqu'à un maximum de 14.3% des patients atteints de cancer et chez jusqu'à un maximum de 5.7% des volontaires lors de la première année suivant le diagnostic. Des analyses de variance (ANOVAs) à mesures répétées ont révélés des taux plus élevés de symptômes de TSPT sur le IES au temps 1 et 2, sur le PCL-C au temps 2, 3 et 4, de dépression au temps 2 et d'anxiété aux temps 1 et 2 chez les hommes atteints de cancer comparativement aux volontaires. Cependant, les deux groupes n'étaient pas différents quant à leur niveau de stress perçu et dans la qualité de vie rapportée. De plus, une augmentation significative des symptômes de TSPT fut observée pour les patients atteints de cancer mais pas pour les volontaires. Les résultats de ces études suggèrent que la détresse, sous la forme de dépression et d'anxiété, était élevée mais tend à diminuer avec le passage du temps. Par ailleurs, les manifestations précoces de TSPT prédisent fortement les symptômes de TSPT à un moment ultérieur et il y a une augmentation des symptômes de TSPT avec le passage du temps. L'évitement et le déni sont communs au moment du diagnostic, mais les intrusions gagnent graduellement de l'importance. Ceci pourrait indiquer qu'une forme de traitement cognitif de l'expérience stressante a lieu qui permettrait aux survivants de revisiter leurs croyances existantes et de faire l'expérience de divers niveaux de croissance post-traumatique.

Mot clés: Trouble de stress post-traumatique, croissance post-traumatique, cancer, détresse, jeunes hommes, traitement cognitif.

ABSTRACT

Testicular and lymphatic cancers (Hodgkin's and non-Hodgkin's disease) are among the most common cancers in young males aged 18 to 45. It has recently been acknowledged that symptoms of posttraumatic stress disorder (PTSD) may be present following a cancer diagnosis, with incidence varying between 1.9% to 35.1% (Kangas, Henry & Bryant, 2002). This project aimed to explore the cancer related symptoms of PTSD and distress, to determine the frequency of PTSD symptoms in young male cancer patients, to establish a timeline for PTSD symptoms in the first year following a cancer diagnosis, to identify risk factors that were predictive of PTSD symptoms, and to report on the coping and posttraumatic growth experienced by survivors. In study 1, verbatim accounts of 22 survivors of either testicular or lymphatic cancer were collected retrospectively. Qualitative data was analyzed according to the Miles and Huberman (1984) approach. Survivors' appraisal of their diagnosis as a being a shock and a threat were common, as were and anxious anticipation, avoidance, and denial. In the treatment phase, despair and discouragement were most common. In the long-term, PTSD symptoms (increased presence of intrusions and avoidance) and delayed emotional reactions were reported. Optimism was common in early coping and many reported posttraumatic growth in the long-term survival phase. These findings were consistent with the social-cognitive transition model of adjustment (Brennan, 2001). In study 2, newly diagnosed cancer patients (n=92) and community controls (n=88) were recruited and followed prospectively over a period of 12 months. Severe PTSD symptoms were observed in up to 14.3% of cancer patients in the first year following diagnosis, compared to 5.7% of controls. Repeated measure analyses of variance (ANOVAs) revealed that cancer patients had higher levels of PTSD symptoms, at time 2 and 4 on the IES, at times 2, 3 and 4 on

the PCL-C, at time 2 for depression, and at times 1 and 2 for anxiety than controls, but were not different in perceived stress, nor in quality of life. Furthermore, there was a significant increase in PTSD symptoms over time. Initial scores of PTSD were the only significant predictor of PTSD at time 4. Furthermore, there was a significant increase in PTSD symptoms over time for the cancer group, but not for controls. Taken together these results suggest that distress in the form of depression and anxiety was elevated but tended to diminish over time. Moreover, early manifestations of PTSD strongly predict later PTSD symptoms and there was an increase in PTSD symptoms over time. Avoidance and denial were common at the time of diagnosis, but intrusions gradually became more important. This may indicate a that a form of cognitive processing of the stressful experience is taking place and allows some survivors to revisit their existing life assumptions and experience differing levels of posttraumatic growth.

Keywords: Posttraumatic stress disorder, posttraumatic growth, cancer, distress, young males, cognitive processing

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LIST OF ABBREVIATIONS

ANCOVA: Analysis of covariance

ANOVA: Analysis of variance

CCS/NCIC: Canadian Cancer Society/National Cancer Institute of Canada

DSM-IV: Diagnostic and Statistical Manual- 4th edition

FACT-G: Functional Assessment of Cancer Therapy-G

IES: Impact of Event Scale

HD: Hodgkin's Disease

LC: Lymphatic Cancer

NHD: Non Hodgkin's Disease

PCL-C: Posttraumatic Stress Disorder Checklist-Civilian

PSS: Perceived Stress Scale

PTSD: Posttraumatic Stress Disorder

SCL-90: Symptoms Checklist-90

SCT: Social-cognitive transition model of adjustment

SRRS: Social Readjustment Rating Scale

TC: Testicular Cancer

STATEMENT OF AUTHORSHIP

I share authorship of the manuscript entitled "From PTSD to posttraumatic growth: Transitional processes associated with the cancer experience" with my thesis supervisor Dr. Zeev Rosberger and with my co-supervisor Dr. Marie Achille. The original idea of for the study was mine and the study was conceptualized by me and Drs. Rosberger and Achille. The data collection was performed by Dr. Rosberger, Dr. Achille, myself and research assistants. The literature review, the choice of theoretical framework, the choice of the specific qualitative analyses and content analyses of qualitative verbatim were performed by me. The manuscript was written by me with contributions from Drs. Rosberger and Achille.

I share authorship of the manuscript entitled "Symptoms of PTSD in young males recently diagnosed with cancer" with my thesis supervisor Dr. Zeev Rosberger and with my co-supervisor Dr. Marie Achille. The original idea for the study was mine and the study was conceptualized by me and Drs. Rosberger and Achille. The data collection was performed by a research coordinator and myself. The literature review and choice of theoretical framework was performed by me. The statistical data analysis was completed by me with guidance provided by Dr. Brett Thombs. The manuscript was written by me with contributions from Drs. Rosberger and Achille.

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SECTION 1: GENERAL INTRODUCTION

The objectives of this project are to explore the cancer-related symptoms of PTSD and distress (depression and anxiety) both retrospectively and prospectively; determine the frequency, evolution and risk factors for PTSD symptoms in young male cancer patients in the first year following a cancer diagnosis; and in addition to examine their experience of coping and posttraumatic growth.

Approximately 40% of Canadian women and 45% of Canadian men will be diagnosed with cancer at some point in their lifetime and 1 out of every 4 Canadians will die from cancer (Canadian Cancer Society /National Cancer Institute of Canada [CCS/NCIC], 2008). In 2008, nearly 30% of new cancer diagnoses (50 000 cases) and 18% of cancer-related deaths (13 000 cases) will occur between the ages of 20 and 59 (CCS/NCIC, 2008). Hence, there is a growing concern to understand the psychological adjustment of younger cancer patients. Cancers such as testicular (TC), Hodgkin's (HD) and non-Hodgkin's (NHD) lymphoma largely occur in young men in the most productive developmental stage of their life (i.e. raising children, building conjugal relationships, employment etc.). In Canada, there will be an estimated 3800 new cases of NHD, 480 new cases of HD and 890 new cases of TC in 2008 in males of all ages (CCS/NCIC, 2008). The low incidence rates of NHD, HD and TC add to the difficulties of studying psychosocial adjustment in this population.

Testicular Cancer

Testicular cancers are almost always germ cell (reproductive cell) tumors. There are two types of TC, seminoma and nonseminoma (CCS/NCIC, 2008; Gilligan, 2007). TC is the most common malignancy in men ages 15 to 45 and accounts for almost 25% of all cancer diagnoses in this age-range (Fossa & Dahl, 2002; Gilligan, 2007; Raemarkers et

al., 2002). The highest rate of five-year relative survival in Canada is for TC (96%), however incidence rates of this malignancy have been increasing (CCS/NCIC, 2008). The risk factors of TC are poorly understood (CCS/NCIC, 2008). Cryptorchidism (delay in the descent of testicles), abnormal development of the testicle, personal or family history of TC, age (particularly between 15 and 49) and infertility (CCS/NCIC, 2008; Gilligan 2007) are some of the possible causes of TC.

TC is most often discovered by the patients themselves as such tumors grow rapidly and are easily palpated. Early detection by regular testicular self-examination may curb disease severity (Gilligan, 2007; Moul, 2007; Simon, 2005). The most common early symptoms for TC are: a lump on the testicle that is almost always painless, feeling of heaviness or dragging in the lower abdomen or scrotum, a dull ache in the lower abdomen and groin (CCS/NCIC, 2008). Unfortunately, TC symptoms may be confounded as resulting from an infection and treated ineffectively with antibiotics which may allow the tumor to grow for an added period of time.

Treatment typically includes one or more of the following: radiation, combination chemotherapy (carboplatin, blenoxane, etoposide and cisplatin) and surgery (orchiodectomy and retroperitoneal lymph node dissection). Radical orchiectomy (surgical removal of the affected testicle) is a standard procedure of the diagnosis work-up (CCS/NCIC, 2008; Gilligan, 2007). With one healthy testicle, patients are still able to have erections and ejaculations, and may still be able to father children. In about 2 to 3% of cases, the second testicle will also develop a malignancy (Gilligan, 2007). In such cases, both testicles are removed and patients are infertile and experience orgasms as dry ejaculations. Before undergoing any systematic or invasive procedure, patients are urged to make use of sperm banking because of the potential for temporary or permanent

infertility following cancer treatments. There are several cancer-related causes of infertility: the systemic effects of the disease itself (for both testicular and lymphatic cancers), the surgical procedures (non-nerve sparing retroperitoneal lymph node dissection, resection of residual node masses, removal of testes), and gonadotoxic chemotherapy and radiotherapy (Hartmann Albrecht, Schmoll, Kuczyk, Kollmannsberger, & Bokemeyer, 1999; Howell & Shalet, 2002; Naysmith, Blake, Harvey, & Johnson, 1998; Schrader, Heicappell, Muller, Straub, & Miller, 2001; Tal, Botchan, Hauser, Yogev, Paz, & Yavetz, 2000). Male cancer patients usually recover spermatogenesis between two to four years post-completion of cytotoxic cancer therapy, but it is currently impossible to predict the likelihood, extent and timing of fertility recovery, and up to 30% of patients may never recover (Colpi, Contalbi, Nerva, Sagone, & Piediferro, 2004; Giwercman & Petersen, 2000).

The spectrum of treatment related late-effects ranges from minor complications to permanent and occasionally lethal sequelae (i.e. cardiac complications, the occurrence of a second malignancy, infertility) (Aziz & Rowland, 2003; Gilligan, 2007). After surgery, pain, nausea, and lack of appetite may be experienced. Radiation side-effects are usually mild and include fatigue, irritation or tenderness of the skin where the treatment was given. The side-effects will usually disappear when the treatment period is over and the normal cells repair themselves. TC responds well to chemotherapy. The treatment is outpatient for most patients and may last from six to ten months (Gilligan, 2007). Although healthy cells can recover over time, patients may experience side-effects from treatment like nausea, vomiting, loss of appetite, fatigue, hair loss and an increased risk of infection. High doses of chemotherapy may also kill normal blood-forming cells in the marrow. Blood transfusions or "blood cell growth factors" to increase red cells may be

needed. To improve white cell count the amount of chemotherapy drugs may be reduced, time between treatments may be increased and growth factors to increase neutrophils may be given. A neutrophil is a type of white cell that fights infection in the body. Bone marrow transplantation (stem cell transplant) is a newer treatment option that uses a patient's own stem cells (autologous infusion) or donated stem cells (allogeneic transplant) to restore blood and immune cell formation after intense chemotherapy or radiation therapy (CCS/NCIC, 2008).

Lymphatic cancers

Lymphomas are a group of blood cancers that start in the lymphatic system. Lymphoma starts with a change to a type of white blood cell called a lymphocyte. The change of the lymphocyte causes it to become a lymphoma cell. The two most prevalent types of lymphoma are HD and NHD. Approximately 15 percent of people with lymphoma have HD; others have one of many different subtypes of NHD (CCS/NCIC, 2008). The 5-year survival rate for males with lymphoma is over 80% (Raemarkers et al., 2002) but NHD generally has a worse prognosis (Jemal et al. 2004). NHD is currently the 5th most common type of cancer across all age groups in Canada (CCS/NCIC, 2008), and the second most prevalent type of cancer in 20 to 44 years of age (CCS/NCIC, 2002). Fortunately, since 2000, mortality rates in males have shown a statistically significant decline of 2.3% per year (CCS/NCIC, 2008).

The risk factors and causes of HD and NHD are also poorly understood and in many cases patients do not show any identifiable risk factors. Infections with the Epstein-Barr virus, the human T-cell lymphocytotropic virus (HTLV), or human immunodeficiency virus (HIV), family history, and age (particularly between 15 and 35 and after 60)

increase the probability of developing HD (Leukemia and Lymphoma Society, 2008). Exposure to pesticides, dioxins and herbicides may also increase the risk of NHD (CCS/NCIC, 2008). Usually the first symptom of HD or NHD lymphoma is swelling of lymph nodes in the neck, armpit, chest, groin, or near the ears or elbows. The enlarged lymph nodes are usually painless. Other signs and symptoms of HD are weight loss, night sweats, unexplained fever, feeling tired, lack of energy, and itchy skin (CCS/NCIC, 2008; Leukemia and Lymphoma Society [LLS], 2008).

Treatment options for lymphomas are chemotherapy, radiation therapy, biological therapy (sometimes called immunotherapy), bone marrow transplant, and peripheral stem cell transplant (LLS, 2008; Theodossiou & Scharzenberger, 2002). Watchful waiting may be recommended in slow growing NHD to avoid side-effects of treatment until it is needed. Lymphomas make it harder for the body's immune system to fight off infections, and chemotherapy and radiation can create complications. A patient who has high-dose chemotherapy may need a stem cell transplant to strengthen the immune system. Some common side-effects from treatment for HD and NHD are: mouth sores, nausea, vomiting, diarrhea, constipation, bladder irritation, blood in the urine, extreme tiredness, fever, cough, rash, hair loss, weakness, tingling sensation, and lung, heart or nerve problems. Fertility may also be compromised temporarily or permanently (CCS/NCIC, 2008; LLS, 2008).

Cancer-related distress

Psychological distress is a recognized side-effect of cancer. According to the clinical Practice Guidelines in Oncology issued by the National Comprehensive Cancer Network (2005, p.1) distress is:

> A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

On average, 35% of patients suffer from elevated levels of distress at some point during their cancer experience (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). The literature generally suggests that breast cancer patients experience significant levels of depression and anxiety (Amir & Ramati, 2002; Andrykowski, Cordova, Studts, & Miller, 1998; Deimling, Kahana, Bowman, & Schaefer, 2002; Epping-Jordan et al., 1999), but some studies suggest otherwise (see: Stiegelis, Hagedoorn, Sanderman, Van der Zee, Buunk, Van der Bergh, 2003).

Cancer-related PTSD

In recent years, researchers became interested in a specific type of distress following cancer diagnosis: posttraumatic stress disorder (PTSD). For the first time in the Diagnostic and Statistical Manual of Mental Disorders-4th edition (DSM-IV) (American Psychiatric Association [APA], 1994) there is recognition that life-threatening illnesses, such as cancer, could be of sufficient magnitude to meet the criteria of a traumatic stressor. One of the peculiarities of PTSD is that it is the only DSM-IV (APA, 1994) diagnosis for which diagnostic criteria includes both etiological and phenomenological aspects of the

illness (Davidson & Foa, 1991). Indeed, PTSD's criterion A qualifies the mandatory stressful event and appraisals leading to symptoms of the disorder. In DSM-IV, criterion A is formulated as follows:

The person has been exposed to a traumatic event in which both of the following were present:

1) *The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others*
2) *The person's response involved intense fear, helplessness, or horror*

The diagnosis of PTSD as it currently stands in the DSM-IV (APA, 1994) requires: 1) the identification of a catastrophic event; 2) the individual's appraisal of the catastrophic event; 3) and the presence of several symptoms directly associated with the initial catastrophic event (e.g., nightmares that occur as part of the disorder are nightmares about the actual event). The list of specific symptoms for PTSD diagnosis remains heterogeneous and requires the presence of symptoms in each of the three major clusters and includes a total of 17 symptoms (DSM-IV, 1994). To receive a diagnosis of PTSD one must have at least one symptom of reexperiencing (intrusions) (i.e.: persistent and uncontrollable thoughts about the event, recurrent dreams about the event, physiological and emotional arousal upon cues resembling the event etc.) (Criterion B), three symptoms of avoidance and numbing (i.e. efforts to avoid thoughts, feelings, conversations, places, and activities associated with the event, incapacity to recall important aspects of the event, restricted range of affect etc.) (Criterion C), and two symptoms of hyperarousal (i.e. irritability, hypervigilance, exaggerated startle response etc.) (Criterion D). As such, a person with 13 symptoms may not meet the specific criteria for PTSD and two

individuals with PTSD may have no common symptoms. While severe stressful experiences lead to high rates of diagnosable PTSD, trauma survivors without the full disorder can also experience high symptomatic levels of subdiagnostic distress (McMillen, North, & Smith, 2000). In fact, some researchers in the field of PTSD have argued that the stringency of the avoidance and numbing criterion (Criterion C) contributes to the low incidence rates of the disorder in some studies (McMillen et al., 2000; Norris, 1992). Criterion C requires a higher number of reported symptoms (three) than the other criteria, and the symptoms in the cluster are some of the rarest (i.e. numbing, amnesia) (McMillen et al., 2000; Norris, 1992). In a sample of hurricane victims, 83% met criterion B, 42% met criterion D but only 6% met criterion C, hence only 5% met the full criteria for PTSD (Norris, 1992). In a sample of earthquake survivors, 13% met the full criteria for PTSD, but when Criterion C was reduced from 3 to 2 symptoms, 26% met the full criteria for PTSD (McMillen et al., 2000).

Because the triggering event plays such a central role in the onset of PTSD, one may put forth the hypothesis that different triggering events may result in different profiles of PTSD. For example, the intrusions experienced by patients diagnosed with a life-threatening illness may be more future-oriented than focused on the past (Kangas, Henry, & Bryant, 2002; Mundy & Baum, 2004). After the initial shock of a diagnosis of cancer, for example, patients have many threats and potential losses to anticipate. The apprehension of such events may intrude more consistently than intrusions regarding the time of the initial shock (Brennan, 2001).

To verify if the breast cancer experience qualified as a traumatic stressor, Cordova et al. (2001) asked patients if they perceived being diagnosed with and treated for breast cancer as a threat of death or serious injury or as a serious threat to their physical

integrity, and if their response ever involved intense fear or helplessness. There were 61% of participants who rated breast cancer as a traumatic stressor. They perceived this event as a threat to life or to physical integrity in 80% of the cases and responses involved fear, helplessness or horror in 64% of survivors.

A review by Kangas et al. (2002) of studies with breast, prostate, neck, gastro-intestinal cancers and Hodgkin's disease patients and studies with heterogeneous samples have shown incidence rates of PTSD varying between 1.9% to 35.1%. This variability in findings is due in part to the different assessment tools used by researchers, by the diversity of populations sampled, and by the time elapsed between diagnosis and the time of data collection (Kangas et al. 2002). Even years after remission, survivors may still present with PTSD symptoms. A study of breast cancer patients by Alter et al. (1996) found that five years post-treatment 4% of women had current PTSD, and 22% had lifetime PTSD (a clinical level of PTSD symptoms at any time after the traumatic event) related to cancer. Other investigations suggest that the prevalence of cancer-related PTSD symptoms may be even higher. In a sample of breast cancer survivors, 52% of the sample scored in the high range of PTSD symptoms on the Impact of Event Scale (IES) (Butler, Koopman, Classen, & Spiegel, 1999). Unfortunately, most studies of PTSD following cancer have been cross-sectional, and many questions remain concerning the applicability of PTSD to cancer as a stressful event. Across the cancer trajectory, which includes many potential threats and losses, it has not been well established whether PTSD symptoms are most present early post-diagnosis or in the post-treatment phase. However, one study identified the diagnosis itself as the principal stressor of the cancer experience in a cross-sectional study with breast cancer patients (Andrykowski et al., 1998). Some studies have concluded that time since treatment is inversely related to PTSD symptoms (Alter et al.

1996; Fleer et al. in press; Kangas, Henry Bryant, 2005a). These studies provide important clues as to the possible course of PTSD symptoms over time.

In a series of papers drawn from a single prospective study (Kangas, Henry Bryant, 2005a, 2005b, 2005c, 2005d), there was significant decline in PTSD symptoms from diagnosis to 1 year post-diagnosis as measured by the Clinician administered PTSD Scale (CAPS), and none of those that had low Acute stress disorder[1] scores at diagnosis developed PTSD at one year, pointing to the importance of early assessment of PTSD symptoms following cancer diagnosis (Kangas et al., 2005a). However, this study also showed that there were significantly more women than men who met the criteria for PTSD at six (47% vs. 13%) and twelve (42% vs. 5%) months (Kangas et al., 2005a, 2005b). Other prospective studies pointed to a decline in PTSD symptoms in general (Manuel, Roth, Keefe, & Brantley, 1987) or in intrusive thoughts but not in avoidance as measured by the IES after diagnosis (Epping-Jordan et al. 1999).

A number of studies and authors have noted the extensive burden that PTSD symptoms pose on individuals (Frueh, Cousins, Hiers, Cavenaugh, Cusack, & Santos, 2002). PTSD symptoms are associated with a reduction in immune response, namely in women with breast cancer (Andersen et al., 1998), an increase in somatic complaints and health problems (Escobar, Canino, Rubio-Stipec, & Bravo, 1992), more emotional disturbance, more pain, and rendering pain resistant to treatments (Aghabeigi, Feinmann, & Harris, 1992). The rate of health service utilization in people with PTSD (38%) is comparable to that found in people suffering from major depression, but higher than that of people with other anxiety disorders (23%) or with substance use disorder (23%)

[1] Acute Stress Disorder is a diagnosis that applies to individuals having been exposed to a traumatic event and who exhibit symptoms for a period of two days to four weeks following the event. A PTSD diagnosis cannot be given to patients until they have exhibited symptoms of the disorder for at least one month.

(Kessler, 2000). Topical neurological research demonstrated a significant reduction in gray matter volume in the right orbitofrontal cortex (which is thought to be involved in the extinction of fear conditioning and the retrieval of emotional memory) of breast cancer survivors with PTSD compared to those without PTSD and compared to healthy subjects both at baseline and follow-up investigations (Hakamata et al. 2007). PTSD is highly comorbid with depression and anxiety (Amir & Ramati, 2002; Deimling et al., 2002; Edgar, Rosberger, Nowlis, 1992; Epping-Jordan et al. 1999) and the vast majority of those who are diagnosed with PTSD will also experience higher risks of suicide, alcohol and/or drug abuse, as well as other types of distress (Haber et al., 2002; Kessler, Borges, & Walter, 1999). Despite these facts, trauma tends to go unrecognized in most outpatient clinics (Frueh et al. 2002).

There are important reasons for studying PTSD, anxiety and depression jointly. PTSD accompanied by depression may have a different prognosis and require different interventions. In a commentary on the complex relationship between PTSD and depression, Neria & Bromet (2000) offered four possible associations: 1) depression can be a risk factor for PTSD; 2) depression can be a consequence of exposure to traumatic events; 3) it can co-occur with PTSD; and 4) it may appear following PTSD. Distress symptoms (such as depression and anxiety) following traumatic exposure often share the same risk factors as PTSD and research has shown that the incidence of PTSD increases the risk for first time major depression (Breslau, Davis, Peterson, & Schultz, 2000). Furthermore, the overlap in quantitative measure of depression, anxiety and PTSD produce quantitatively high collinearity. The relationship among these variables must be examined concurrently to ensure further understanding of these interactions.

Risk factors for PTSD

There is a paucity of research addressing the particular psychosocial needs of male cancer survivors. Most research in psychosocial oncology has been done in samples of breast cancer patients or in mixed-gender samples, without clear comparisons between male and female samples (Andrykowsky, Brady, & Hunt, 1993; Kangas et al., 2005a, 2005b; Stiegelis et al. 2003). However, women are twice as likely as men to develop PTSD in their lifetimes (10.4% vs 5%) even though men have a broadly higher risk of being exposed to traumatic events in their lifetime (Kessler, Sonnega, Bromet, Hughes & Nelson, 1995). There are 60.7% of men and 51.2% of women who reported at least one traumatic event in their lives (Kessler et al. 1995). Yet, the higher risk of PTSD in women is one of the most consistent finding in the epidemiology of posttraumatic stress disorder (Olff, Langeland, Draijer, & Gersons, 2007).

Particular risk factors of cancer-related PTSD are principally linked to two of the major symptom clusters of PTSD: intrusions and avoidance. Most studies have used the Impact of Events Scale (IES) (Horowitz, 1979) as a proxy for PTSD. This questionnaire assesses only intrusive and avoidant symptoms. Lower age is related to increased symptoms of intrusions and avoidance in long-term breast cancer survivors (Butler et al., 1999), as well as newly diagnosed breast cancer patients (Epping-Jordan et al. 1999). Other variables such as lower education (Cordova, Andrykowski, Kenady, McGrath, Sloan, & Redd, 1995; Epping-Jordan et al. 1995) and lower income (Cordova et al. 1995) are also associated with an increased presence of PTSD symptoms in breast cancer patients. In a study of TC survivors (Fleer et al. in press), high scores on the IES were associated with being younger, single, unemployed, and treated more recently. There is no evidence of a relation between disease stage, or total number of treatments received

and subsequent PTSD (Cordova et al. 2001; Kangas et al, 2002; Kangas et al. 2005a, 2005b).

Cognitive Processing and Posttraumatic Growth

Highly stressful events may overwhelm survivors (Brennan, 2001). Thus, avoidance may be part of the normal adaptive process that preserve a coherent mental model of the world, while defending against threatening and painful information that cannot be easily integrated into the assumptive world (Brennan, 2001). However, while avoidance may be an adaptive short-term mechanism it may become counter-productive if it goes on for too long as it prevents adequate cognitive processing (Brennan, 2001; McMillen et al., 2000, Foa, Stekee, Rothbaum, 1989; Suls & Fletcher, 1985).

A theme that runs across cognitive theories of healthy adaptation to extremely stressful events is that adjustment stems out of the repeated confrontation with the memories of the trauma (Brennan, 2001; Creamer, Burgess, Pattison, 1990, 1992; Greenberg, 1995). Positive appraisals and reappraisals of a traumatic event may protect against developing PTSD (Olff et al., 2007). They have been linked to faster cortisol habituation to subsequent stressors, indicating a greater flexibility in the system (Epel, McEwen, & Ickovics, 1998). Thus avoidance, more than intrusions may lead to increased distress by preventing the direct confrontation and cognitive processing of the stressful memories (Creamer et al., 1992). The importance of avoidance and numbing symptoms in predicting the development of psychopathology is also reflected in the importance given to Criterion C in the DSM-IV.

While the thoughts and memories associated with the stressful event are cognitively processed, they may be replaced by other adaptive schemas, which produce posttraumatic growth. There is a growing body of research suggesting that 60% to 90% of cancer

survivors experience posttraumatic growth (Collins, Taylor, & Skolan, 1990). Posttraumatic growth results when individuals having faced life crises experience a positive outcome (Tedeschi and Calhoun 2004). Growth may manifest itself across a variety of domains, such as having an increased gratitude for life, feeling like a stronger person, valuing deeper interpersonal relationships, developing a more meaningful spirituality, or experiencing a richer existence (Tedeschi and Calhoun 2004). In past years posttraumatic growth following exposure to extreme events has been frequently reported and researchers have given many formulations to this phenomenon. It can be viewed as positive illusions (Taylor & Armor, 1996), as a coping process (Aldwin, 1994), as a form of meaning-making (Park & Folkman, 1997), and as benefit finding (Affleck & Tennen, 1996). Posttraumatic growth may be a form of coping, an outcome on its own or both (Cordova, 2001).

Posttraumatic growth occurs because events have forced an individual to revisit the long-held assumptions and beliefs about the self, others and the world. Individuals develop and rely on a general set of beliefs and assumptions about the world that guide their actions, and help them to understand the causes of events. This can provide them with a general sense of meaning and purpose (Janoff-Bulman, 1992). This is also consistent with Taylor's theory of cognitive adaptation to threatening events that predicts that cancer patients would attempt to construe personal benefit from their experience in an effort to protect self-esteem (Taylor, 1983). When individuals are faced with threatening events, they are motivated to derive meaning from their experience as well as to maintain or enhance self-esteem in the face of any negative sequelae associated with the event (Taylor, 1983). This theory predicts that cancer patients would attempt to construe personal benefit from their experience in an effort to protect self-esteem (Taylor,

1983). Psychosocial transitions and growth are also consistent with existential theory: being confronted with one's mortality may elicit a reevaluation and redefinition of life goals and priorities, such that individuals emerge with a greater investment in and appreciation of life, interpersonal relationships, and spirituality and personal resources (Cordova et al, 2001).

Traumatic events may cause a discontinuity in identity because it is being seriously challenged by the extreme experience (Little, Paul, Jordens, & Sayers, 2002). Traumatic events shatter people's basic assumptions about the world; they overwhelm usual coping methods that give people a sense of control, connection and meaning (Herman, 1992). This forces sufferers to reorganize their world view and to search for new meanings. PTSD distorts the normal appraisal process: people with the disorder see the world differently. There is difficulty in discriminating danger cues from safety cues as a consequence of exposure to a significant stressor that is both unpredictable and uncontrollable (Friedman, 1997). The narrative of trauma includes a notion of trauma as a turning point: then the world is experienced as before and after the trauma (Tedeschi & Calhoun, 2004). Identity also includes future memories of the self, which involve the imagination of events that have yet to occur, they are the expectations we create for ourselves and form continuity within our lives (Little et al. 2002). For example, a young male who is a medical student has formed a future vision of himself as being a successful physician, a future husband to his girlfriend and a future father. All of these narrative identities are threatened by the cancer diagnosis. Growth, however, does not occur as a direct result of trauma. It is the individual's struggle with the new reality in the aftermath of trauma that is crucial in determining the posttraumatic growth. Cognitive rebuilding takes into account the changed

reality of one's life after the trauma and produces schemas that incorporate the trauma. It is a consequence of attempts at survival (Tedeschi & Calhoun, 2004).

Rationale and Purpose

This project is part of a larger study examining the clinical, biological, psychosocial impact of disease and chemotherapy treatment effects (including those on reproductive functioning) in men treated for testicular or lymphatic cancer and provides a unique opportunity to study both retrospective and longitudinal subjective experiences of the particular risk factors, correlates and incidence of PTSD in young male cancer patients. The present study is taking place within the psychosocial arm of this larger study, and is composed of two parts. In study 1, retrospective accounts of the cancer experience are gathered from semi-structured interviews with a group of long-term survivors. In study 2, a longitudinal quantitative investigation of newly diagnosed testicular or lymphatic cancer patients looks at the frequency, course and risk factors of PTSD symptoms.

The main purpose of study 1 is to gather qualitative descriptions of traumatic symptoms and identify recurrent themes in a sample of cancer survivors regarding specific aspects of their cancer experience. Particularly, the transition and transformations of cancer-related PTSD symptoms through time (diagnosis, treatment and long-term survivorship) are explored. The appraisal of the cancer experience at diagnosis, treatment and long-term survivorship phases are described with the goal of verifying if and what aspects of cancer are appraised as traumatic. Also, the study describes carefully how shared manifestations of different disorders are more closely related to a specific disorder (i.e. anxiety) than another (i.e. PTSD) at different time points. The final goal of study 1 is to understand the seemingly contradictory reports of distress and posttraumatic growth and to bring these findings coherently within the available theoretical models of

adjustment. It is hypothesized that qualitative accounts from survivors will reveal experiences of psychological turmoil. We also expect that patients will move dynamically from distress to posttraumatic growth and that appraisals and reappraisals about cancer will play a key role in this transition. This part of the study will facilitate the generation of hypotheses regarding the development of PTSD following cancer diagnosis.

Qualitative research attempts to provide an understanding of the experiences, attitudes, beliefs and behaviours of social actors as they live through a situation (Elliot, Fischer, & Rennie, 1999). In data gathering and analysis, the qualitative researcher attempts to reflect the understanding of the participants, staying close to the perspective and meaning that the interviewee has provided. While it cannot provide causal explanations of phenomena, qualitative research can enrich understanding by providing a theory on observed data and by providing meaningful answers to questions under study (Elliot et al., 1999). Previous studies using qualitative methods have examined the experience of male cancer survivors to develop an understanding of the important domains of the experience. In a study of sexual dysfunctions in men following testicular cancer, qualitative analysis generated results not otherwise found with the use of quantitative self-reported questionnaires (Sheppard and Wylie, 2001). This approach has allowed the uncovering of marked variability in the expression of emotional reactions and psychological effects of infertility within a small sample of young male cancer survivors (Green, Galvin, Horne, 2003). While PTSD has yet to be studied in this population, a qualitative investigation of the experience of testicular cancer survivors at least 3 years post-treatment revealed themes of disbelief and despair, guarded optimism, "feeling under siege" and experiences of physical and emotional challenges (Brodsky, 1999).

Qualitative studies are particularly well suited for the investigation of poorly understood phenomena; by generating themes and hypotheses related to study questions.

The purpose of study 2 is to examine PTSD symptoms in testicular and lymphatic cancer patients and try to establish a timeline for the emergence of PTSD symptoms in the first year following cancer diagnosis (time 1: diagnosis, time 2: 3 months post-diagnosis, time 3: 6 months post-diagnosis and time 4: 12 months post-diagnosis). Study 2 aims at identifying the frequency, risk factors, and course of PTSD symptoms. Psychological morbidity will be assessed to gain an understanding of the relationship between PTSD, depression and anxiety in this group. It is hypothesized that: a) incidence rates of PTSD symptoms will be higher at all time points in cancer patients than in a group of healthy controls from the community, b) levels of PTSD at a previous measuring time will highly predict current levels of PTSD, c) the highest level of PTSD symptoms in patients will be at the time of diagnosis and will steadily decrease through time, d) younger age, prior history of trauma, lower education level and lower socioeconomic status will increase the likelihood of PTSD symptoms, and e) PTSD will be highly correlated to depression and anxiety.

SECTION 2: FROM PTSD TO POSTTRAUMATIC GROWTH: TRANSITIONAL PROCESSES ASSOCIATED WITH THE CANCER EXPERIENCE

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Abstract

A cancer diagnosis can be a highly distressing experience, yet some survivors also experience positive psychosocial outcomes. This study explores the transitional processes and development of PTSD symptoms, appraisals, distress, coping and posttraumatic growth over time. Verbatim accounts of 22 survivors of either testicular or lymphatic cancer were gathered retrospectively. Qualitative data was analyzed according to the Miles and Huberman (1984) approach. Diagnosis was appraised as a shock and threat, and anxious anticipation and denial were common. In the treatment phase, despair and discouragement were most common. In the long-term, PTSD symptoms and delayed emotional reactions were reported. Optimism was common in terms of early coping and many reported posttraumatic growth in the long-term survival phase. Findings are consistent with the Social-Cognitive Transition model of Adjustment. Conclusion: While distress is present throughout the cancer experience, some survivors revisit their existing life assumptions and experience differing levels of posttraumatic growth.

Introduction

Testicular cancer (TC) and Lymphatic cancer (LC) (Hodgkin's (HD) and Non-Hodgkin's disease (NHD)) are currently the two most common types of cancer in men 45 years of age or younger (Canadian Cancer Statistics/National Cancer Institute of Canada, 2002, Trask, Paterson, Fardig, & Smith, 2003). Fortunately, due to recent medical and technological breakthroughs, the 5-year survival rate for testicular cancer is 90-95% (Fossa & Dahl, 2002; Kaasa, Aass, Mastekaasa, Lund, & Fossa, 1991) and for lymphomas this rate is over 80% (Raemarkers et al., 2002) but NHD generally has a worse prognosis (Jemal et al. 2004). As both incidence rates and rates of survival increase, more men will become long-term survivors of these cancers. Both cancers are treated with similar chemotherapy regimens, with similar side-effect profiles, including potential infertility, and both show excellent prognosis. Also, psychosocial outcomes are similar in these two cancer populations (Bloom et al., 1993). The cancer experience is an ongoing event associated with several potential threats and losses. The trajectory experience involves multiple stages as the patient passes through the possible threats of diagnosis, surgery, drug treatments, side-effects, and the survival and recovery period. Following a traumatic event it is common that an acute stress response emerges and may evolve into a chronic state of emotional dysregulation, but, for most, these symptoms will resolve. However, we lack an understanding of the developmental timeline of these symptoms and of the factors that lead to a timely return to homeostasis following such potentially traumatic events.

Unlike previous editions, the DSM-IV (American Psychiatric Association [APA], 4th Edition, 1994) recognizes that the diagnosis of a life-threatening illness, such as cancer, can be of sufficient magnitude to meet the criteria of a traumatic stressor. Presumably the

traumatic event in relation to cancer is the diagnosis itself. Apart from being exposed to a seriously stressful event, the person's subjective response to this event must have included intense fear, helplessness, or horror in order to qualify for a PTSD diagnosis. It is patients' subjective appraisals of the cancer experience that reveal when and how they perceive cancer as a threat. In PTSD, appraisal implies that an event is a threat, and a judgment of the seriousness of that threat. It includes giving a meaning to the threat and an emotional experience. The three symptom clusters necessary for diagnosing PTSD include: a) intrusions: persistent and uncontrollable thoughts about the event, b) avoidance and numbing: efforts to avoid thoughts, feelings, conversations, places, and activities associated with the event, restricted range of affect, feeling detached from others, diminished interest in significant activities, and c) hypervigilance: increased arousal, exaggerated startle response, difficulty concentrating.

A review of PTSD in cancer populations revealed a prevalence of PTSD varying between 1.9% to 35.1% (Kangas, Henry, & Bryant, 2002). In lymphatic cancer and testicular cancer survivors these figures are respectively 17% (Black & White, 2005) and 13% (Fleer et al., in press). This variability in findings is due likely to the different assessment tools used by researchers, the diversity of populations sampled, small sample sizes and by the time elapsed between diagnosis or end of treatment and the time of data collection. A study of head and neck cancer patients showed that while a small percentage of women met the full criteria for PTSD 12 months post-diagnosis (14%), these were the same patients who had met criteria at 6 months post-diagnosis (Kangas, Henry, & Bryant, 2005). There were no new cases of PTSD at 12 months (Kangas et al., 2005). These studies point to the pervasiveness of early PTSD manifestation and the need

to investigate early PTSD manifestations in order to uncover factors that lead to unremitting (chronic) forms of the disorder over time.

General distress is a common side-effect of cancer. In the case of Hodgkin's and non-Hodgkin's lymphoma patients, elevated distress was present in 37.8% and 36.6% respectively, placing these cancers as the 3rd and 5th most distressing types of cancer after lung, brain, and pancreatic cancers (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). While Zabora et al. (2001) did not provide similar norms for testis cancer patients, Bloom et al. (1993) found no significant differences on psychological outcomes and distress in a comparative study of testicular cancer patients and Hodgkin's lymphoma patients. Given that PTSD is highly comorbid with depression, anxiety and other types of distress (Amir & Ramati, 2002; Deimling, Kahana, Bowman, & Schaefer, 2002; Edgar, Rosberger, & Nowlis, 1992; Epping-Jordan et al., 1999), symptoms of these disorders are likely to be elevated in young males with cancer. The overlap between these disorders is huge. When scales of depression, anxiety and PTSD are given, they always correlate highly, and thus can tell us little about the differentiation among these disorders. For example, "markedly diminished interest or participation in significant activities" is a symptom frequently observed in major depression; however in PTSD this diminished interest appears only following the stressful event. To give another illustration, "difficulty falling or staying asleep" is a symptom of primary insomnia, generalized anxiety disorder and major depression, to list a few; again in PTSD sleep disturbances are directly attributable to the initial stressful event. Qualitative investigations are needed to describe the co-occurrence of these disorders and perhaps to clarify when a symptom is a property of one specific disorder versus another.

Despite the evidence for distress following cancer, there is a growing body of research that has explored the positive benefits that may result from being confronted with a traumatic event (Jaffe, 1985; Tedeschi & Calhoun, 2004). In the area of psychosocial oncology, despite the hardship of a cancer diagnosis, some survivors experience posttraumatic growth, such as growth in relating to others, spiritual change, and greater appreciation of life (Andrykowsky, Brady, & Hunt, 1993; Carver & Antoni, 2004; Cordova, Cunningham, Carlson, & Andrykowski, 2001). Tedeschi and Calhoun (2004, p.1) have provided the following definition of posttraumatic growth:

> Posttraumatic growth is the experience of positive change that occurs as a result of the struggle with highly challenging life crises. It is manifested in a variety of ways, including an increased appreciation of life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life.

Posttraumatic growth is a possible outcome of adapting to traumatic events. In contrast to coping mechanisms, posttraumatic growth is an ongoing process that gives sense to the experience. There is a discontinuity in time as life is perceived as before versus after the trauma. The present study retrospectively explores the transition and transformations of cancer-related PTSD symptoms through time (diagnosis, treatment and long-term survivorship) and describes the appraisal of the cancer experience at diagnosis, treatment and long-term survivorship phases with the goal of verifying if and what aspects of cancer are appraised as traumatic. Also, the study describes how shared manifestations of different disorders are more closely related to a specific disorder (i.e. anxiety) than another (i.e. PTSD) at different time points. The final goal of this paper is to understand the seemingly contradictory reports of distress and posttraumatic growth

and to bring these findings together coherently within the available theoretical models of adjustment. We expect that patients will move dynamically from distress to posttraumatic growth and that appraisals and reappraisals about cancer will play a key part in this transition.

Methods

Study Design and procedures

This qualitative study employed semi-structured individual interviews with male cancer survivors. Interviews were approximately 90 minutes and were conducted in English or French by trained interviewers. The team of interviewers was composed of four graduate students in psychology. Verbatim transcription of the interviews was performed by the interviewers and a paid research assistant. Ethics approval was obtained through a university institutional review board prior to the beginning of the study. Written consent was also obtained from each participant. The sample consisted of 22 males, TC (n=12) and LC (Hodgkin's Lymphoma n=9; Non-Hodgkin's Lymphoma n=1) survivors. Cancer survivors were recruited through referrals from hospitals and private practices in the Montreal area (Canada, Province of Quebec). Patients were identified by physicians from two university hospitals in large urban area and subsequently recruited by a research coordinator once they met eligibility criteria. Inclusion criteria in this study were: having received a diagnosis of testicular cancer, Hodgkin's or Non-Hodgkin's lymphoma, being at least 1-10 years post completion of treatment, having received chemotherapy as part of their treatment regimen, and being between 18 to 40 years old at time of initial cancer diagnosis. In this study internal diversification was accomplished by selecting survivors who were between one to ten years post-completion of cancer treatments and ages 18 to 40 at the time of diagnosis, thus allowing for assessment of distress and coping at

different stages of survivorship and developmental maturity. Internal homogeneity of the sample was achieved by selecting only survivors who had undergone gonadotoxic chemotherapy treatments for TC or LC. Patients were recruited until data saturation was reached, in other words until the addition of novel interviews only reiterated information that had already been collected in prior interviews without adding any novel information. Data saturation was reached after 15 interviews. However, we proceeded with recruitment to include five more Hodgkin's disease survivors and one Non-Hodgkin's disease survivor to increase internal diversification. Demographic data was gathered prior to the interview.

This project is part of a larger study that explored communication between health care professionals and patients concerning fertility issues, long-term adaptation, as well as the relationship between psychosocial adjustment, informational needs and communication processes surrounding disease and its side-effects in young men diagnosed with testicular or lymphatic cancer and at risk for infertility. These questions were elaborated from the literature, a pilot qualitative study and a consensus among two clinical psychologists and a urologist/reproductive specialist, all of whom were experienced in psychosocial oncology research and practice. Also as coding and analysis of interviews evolved, additional questions were included in the interview guide to validate and explore the new information emerging from the coding. As such, the participant's description of their psychological adjustment was incorporated as probes and questions in the interview guide as the project evolved. Interviews consisted of open-ended questions and specific probes regarding four major domains a) the general experience of cancer (i.e.: What was your reaction to the cancer diagnosis?, What was your experience in terms of treatment and side-effects?); b) the communication surrounding fertility related issues (i.e.: When

was infertility first brought up?); c) the psychological impact of cancer and chemotherapy induced infertility and sexual dysfunctions (i.e: Did you avoid the topic of cancer at all or avoid reminders of it? Did you react with intense fear at any point?); and d) patient needs regarding effective communication around fertility issues (i.e.: What would help patients feel more comfortable, better prepared and more efficient in discussing infertility issues in the future?). The current study was particularly focused on the first and third interview domains, specifically data reflecting PTSD, distress (depressed mood and anxiety), posttraumatic growth and coping.

Data analysis

Interviews were audio taped, transcribed verbatim, and imported into N'Vivo 2.0 software. The data was gathered and analysed according to the Miles and Huberman (1984) mixed approach. This approach consists of three flows of analysis: data reduction into theme codes, data display into tables, and conclusion drawing and verification. This particular study places itself between the post positivist and the constructivist paradigms (Ponterotto, 2005). The mixed approach aims at elaborating a systematic (but not necessarily exhaustive) description and a theory about a phenomenon. This data analysis method has proven rigorous and has already been used by researchers in psychosocial oncology (Thewes, Butow, Girgis, & Pendlebury, 2004; Thewes, Meiser, Rickard, & Friedlander, 2003) and proves to be particularly suited for the study of new and poorly understood phenomena.

In the first step of analysis, similar themes that emerged from the narrative text were regrouped into categories (units of analysis). Similar themes were grouped into overarching trees (metacodes) and subcategories of these metacodes were placed in branches under these, themes having no apparent relation to other categories were kept

separately. The first interview was coded by a team of two members from the research group and codes were elaborated through discussion and agreement on themes. The second interview was coded by another team of two coders using the initial framework developed by the two other coders. Coders then met with the research team as a whole to refine the coding framework and achieve consensus. Once that was established, the coders proceeded to the coding of the remaining interviews. New codes were added as new themes emerged and the coding team met frequently together with the whole research team to achieve inter-coder consensus. Codes reflected categories set a priori from the interview package, from the literature reviewed and most importantly from the themes that emerged from the data. Coders also kept detailed memos, résumés and field notes during this process. Analyses continued until saturation was established and no new themes emerged from the data. Once the initial coding was performed, the first author of this study proceeded to a more in-depth recoding of categories of interest for the present study. For example, under the category of distress at diagnosis, the first author proceeded to refining subcategories of distress symptoms. Once the coding was finished the first author proceeded with the next analytical steps.

In the second step of analysis, data display, the narrative text now broken down into codes was displayed in either tables or matrices that allowed for the categorization of large sum of data into manageable amounts of information (Miles & Huberman, 1984). In the present study, three types of matrices were used: a) checklist matrices, which is a table that may contain a scaling function (i.e. not at all, somewhat, quite a bit, very much) and allows to assess to presence of specific elements from the participants verbatim; b) time-ordered matrices: patient's experience is entered in a table arranged following a time sequence to see if a reported change occurs and c) conceptually

clustered matrices, which cluster research questions that belong together to see possible links between them. We used checklist matrices to verify and count the presence of distress and PTSD symptoms according to the DSM-IV-TR (American Psychiatric Association [APA], 4th Edition, 1994). We used time-ordered matrices to gain a temporal sense of distress symptoms within and across each individual over the key time points of diagnosis; treatment and long-term survival. We used conceptually clustered matrices to display logical patterns and associations between themes that seemed to belong together.

In the third step, conclusion drawing and verification, a number of strategies were used to confirm interpretation, avoid biases, and insure that conclusions are well founded. The goal is to insure that interpretation of the data is valid, reproducible and accurate (Huberman & Miles, 1991). The strategies most applicable to the present study included search for plausibility, regrouping variables, looking for patterns, and identifying relations between variables (Huberman & Miles, 1991). We also sought to identify whether a larger conceptualization or existing theory of adjustment to illnesses could help organize the findings and provide a conceptual and theoretical framework that would lend greater plausibility to the results. This strategy of achieving theoretical or conceptual coherence is also described by Miles and Huberman (1991).

Findings

Sample characteristics

At the time of the interview, the age of participants ranged from 20 to 54 years (mean = 32.7), and at the time of diagnosis the age range of participants was 18-41 years (mean = 26.4). Time since diagnosis was on average 6.3 years (range =1-10). Most of the participants were currently employed in full-time work (n=20), one was retired and one

was temporarily not working. With regards to family income: nine patients had an income of $59000 or less, four had an income between $60000 and $99000 and eight had an income of over $100000 (one participant refused to answer). At the time of their diagnosis, seven participants were single, five were married, two were in a common-law union, three were in a long-term relationship, two were in a recent relationship, one was divorced and one was widowed. All 22 survivors had received chemotherapy. Three Hodgkin's lymphoma survivors received chemotherapy alone. Nine testicular cancer and three Hodgkin's lymphoma survivors received a combination of surgery and chemotherapy. Three testicular, one non-Hodgkin's lymphoma and three Hodgkin's lymphoma survivors had chemotherapy, surgery and radiotherapy. To understand the genesis and possible transitional processes of PTSD symptoms, distress, coping and posttraumatic growth qualitative themes were organized across three areas over the cancer trajectory: diagnosis, treatment and long-term survival phases. In table 1, the data is organized according to this timeline, and illustrates how symptoms evolve, appear or disappear from one phase to the next.

Psychological reactions at diagnosis

In terms of initial appraisal of the stressful event of the cancer diagnosis, the subjective criteria of fear, horror and helplessness of PTSD were investigated. When asked to recall their initial psychological reaction when the cancer diagnosis was first announced, almost half of survivors mentioned they experienced shock, or a sensation akin to depersonalisation:

> Yeah, it was like I was watching and I wasn't in the room. (...) She was just giving me all this information and my mouth was just open like a deer in the headlights. She was telling it to me, and she was repeating it, but I didn't

> understand it. That meeting was a little bit scary. Is this real? It's like you're watching it on TV.

Survivors had not expected their diagnosis to be so serious, they expected a benign infection or something of the sort; they were taken by surprise because of their relative young age. Yet, there were survivors who did anticipate the diagnosis of cancer and the news was a confirmation of what they had feared. "To me it wasn't a surprise. I had pretty much expected it to be cancer."

In a similar vein, the fear of death and a sense of foreshortened future were themes described by several participants. Nonetheless, there were about as many survivors who recalled having been immediately reassured by their physician and felt no fear of dying. In spite of this, in a more general manner, at the time of diagnosis survivors reported having felt a fear of the unknown (being unfamiliar with medical treatments and procedures, having to rearrange their lives, etc.) feeling apprehensive about the future and possible medical problems. These themes also point to an appraisal of the diagnosis with helplessness and horror, patients describe a feeling of being afraid and unable to manage the situation:

> Well it's mostly fear, fear of the unknown. You don't know what is coming up. (...) In this case for me it was a total void, I've never had someone close to me who had cancer, well yes, from far, far removed you hear things, but that's what is scary, you don't get real feedback from people you've known, you just get the horror movies that are on television. And it has not been a long time since people recover from cancer. In all the stories you've heard before, well it's people dying, it is people who don't have any more hair, that are bony, and it's the hell of chemotherapy, and the hell of cancer. It's all of that that you see coming down

> without you having nothing to hold on to... about the truth of what it is because you have no truth and there is no one around you that can help you.

Thinking about the cancer diagnosis was emotionally painful; many stopped themselves from thinking about it because they reported it had a negative effect on them. Similarly, some survivors recalled a blunted emotional reaction and others recalled having experienced denial in the initial phase following the cancer diagnosis:

> I didn't feel as much emotion as you might have thought, I didn't start to cry, I didn't start to worry, it was just like a ... from then on I've put one some sort of.. you know a sheet (curtain) to hide from my emotions and I've never felt any emotions after that for about another year.

Few PTSD symptoms were immediately apparent at the time of diagnosis. Symptoms of avoidance were brought up by a minority of survivors. Initial reaction were more closely akin to denial than to avoidance, with patients experiencing much of a shock, for these patients having conversations about the cancer was out of the question and they claimed they had to let some time go by before they could address the topic. One person reported intrusive thoughts, mostly in the form of anxious worry about future physical appearance and the ability to perform sexually in the future. This survivor explained that he dealt with these recurring thoughts by avoidance. There was one survivor who experienced nightmares related to the cancer diagnosis, but there were no reports of intrusive thoughts in the form of reliving the cancer diagnosis:

> Mostly about that, it was and it was extremely depressing, so I just, you know, put it out of my mind, and again right after the surgery when things did not look normal it was like what if I can't perform anymore, what if you hear all kinds of stories about, you know what happens and all kinds of things like that. It's

> something that you just don't want to think about. It was very scary and for me I guess the best way to deal with it was just to stop it. Avoid thinking about it and you're not doing yourself any good until a certain amount of time happens and then seek professional help if necessary. Other than that: just stop it!

Survivors talked about the cancer diagnosis as a life-altering experience. Also, some stated that they experienced a form of existential crisis, questioning the reason why they were hit by cancer. For some patients, the result of this self-questioning led to early acceptance of their illness:

> I used to think like well why? Like I'm 25 years old and I'm in good shape why would this happen to me, I went through that whole thing...it's not fair...why me? Then it occurred to me (...) well you know what, to somebody else I'm someone...you know you always say it only happens to other people, well to that person over there I'm other people, to you I'm other people, so I kind of thought like it's silly for me to put myself through that type of torture...like asking myself that question...why me when it's going to happen to somebody and to all these other people you're other people, you think it only happens to other people, well they think the same thing, at that point I just kind of I accepted it.

In addition to PTSD symptoms, survivors reported many manifestations of distress, they talked about sadness and depressed mood in this period. Survivors recalled having outburst of tears, feeling overwhelmed by a mix of emotions (anger, fear, sadness, and others) and feeling that others could move on with their lives but not them:

> I started crying and it was kind of very fast in my mind, I was trying to figure out all the implications of it (...) I cried and I realized (...) the next day I would not be doing what I thought I would be doing.

Psychological reactions during treatment

During the treatment phase shock receded and gave way to other types of PTSD manifestations. Avoidance of reminders of cancer became more prominent at this point with more participants recalling this symptom. Participants avoided conversations and reminders of cancer such as watching movies depicting cancer patients, and some avoided asking questions or gaining extra information about their cancer because they thought they would not know how to interpret it. One survivor also mentioned that being rushed through the process of treatment and the structured administration of chemotherapy prevented him from processing the experience emotionally; he qualified this occurrence as a good thing, because it allowed him to avoid dealing emotionally. Likewise, some openly denied that cancer had an emotional impact on them:

> I would say definitely that I would, whether it was consciously or subconsciously, avoid some things yes, I would, and I think also now that I think a bit there's also that typical like male macho thing where I was thinking also that you know what I can handle this on my own, I don't need any help...you know psychologically and physically where I thought that I could handle it on my own. Sometimes I thought I could and other times not so much.

Recurring intrusive thoughts were still infrequently reported, while the presence of nightmares was reported by the same individual as at diagnosis. Another category of PTSD symptoms made its appearance at this time: hypervigilance in the form of excessive monitoring of symptoms and going for extra medical check-ups was mentioned by one survivor. Content of cancer-related anxiety was diverse and wide-reaching. A strong apprehension about the future was an issue for numerous participants. There was worry about the disease and its possible complications, nervousness and stress before

chemotherapy rounds, being worried about the impact on loved ones and the anxiety about the financial burden associated with being sick.

During the treatment period depressed mood was the most salient distress symptom and was reported to a larger extent than other PTSD symptoms with more than half of survivors making mention of depressed mood in the interviews. For several survivors depressed mood was synonymous with despair during the treatment phase. It is noteworthy that the treatment period is the only time point where survivors recalled feelings of despair. These survivors had periods when they thought they would never recuperate; they thought death was near or that they would never be able to enjoy a healthy life again. "Getting up in the morning as if you had not slept for two days... I sometimes had the impression that it wouldn't end. I asked myself when I will ever be able to recuperate?"

Survivors also admitted having had thoughts of death during treatment and having had such difficulty that they reached a point where they did not care if they lived or not. In addition, a few said that if they had a cancer recurrence, they would rather die than go back to chemotherapy. "I would not go through that again. If it comes back, I'm going to die right away. I will not go through that again it is too hard emotionally."

Post-treatment and long-term psychological impact

We also questioned participants about the impact of cancer after the end of treatment and through the long-term survivorship phase. Following treatment, there was an increase in the salience and diversity of reported PTSD symptoms and in the number of survivors who experienced them. When asked about the long-term emotional or psychological impact of cancer a few survivors spontaneously said they suffered some type of delayed emotional reaction or posttraumatic stress. "It took a good year, they call it posttraumatic

stress something, because a year after, when everything was over and things are supposed to go well, when they gave me the OK everything is good, that's when it hit me." "No, during the treatments I still hadn't accepted that I had it. It hadn't sunk in that I had cancer. I only accepted I had cancer once the last treatment was done."

Furthermore, avoidance of reminders of the illness was the most often reported PTSD symptom in the long-term survivorship phase. Also, avoidance became a conscious process, a volitional action, which differed from the sense of unconscious denial following the shock of diagnosis. About half of the participants said they would either avoid conversations, places, images or things that reminded them of the cancer experience. "I press the mute button if I see a commercial that talks about that. I don't like to hear about it so much." "Right now, in my head I'm trying to think that I was never sick. Even though I meet people I just don't mention that I was sick, except trying to forget about it."

Symptoms of intrusions in the form of repeated unpleasant thoughts appeared with more importance at the end of treatment. Survivors recalled having thoughts of cancer everyday, "seeing" cancer everywhere, and thinking about it when they didn't mean to:

> It's clear that you can't forget it. There was a time where there wasn't one day where I didn't think about it (...). The first times you have a headache: its brain cancer. You know, your back hurts and that's it: your tumor is back. I had an episode recently where I had pain in my abdomen and I was really scared, because the fear isn't the same because of the fact that I have kids now.

The previous quote poignantly exemplifies the hypervigilance that many survivors shared after cancer and increased fear about the future and the possible secondary impacts of cancer on their lives. Specifically individuals mentioned a fear of recurrence

and mentioned a fear about possible secondary impact of cancer on their lives such as limiting their parenthood years or general activities. Survivors who worried about recurrence shared that they could not get closure, that nothing could reassure them about the future, especially at a time when the medical team was no longer following them closely. These were additional concerns that appear only once the cancer episode is in remission:

> Well the minute you take a shower and you're washing your hand and you feel a little lump in the back, right away I go oh, is it back? So it's the fear of recurrence? Oh, yeah...big time. Oh yeah. Since the end of the treatment the fear of it coming back definitely...it's a big fear.

Some survivors reported emotional numbing, feeling detached from the experience, and one survivor reported trouble remembering important parts of the experience. While alcohol and drug abuse are not part of the classic PTSD criteria, substance abuse is a highly prevalent comorbid condition to PTSD (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). Some survivors who linked the substance abuse to a process of emotional numbing reported these behaviors; they describe it as an illustration of how drastically they were affected by the cancer experience:

> I realized that I was at the point where I was doing myself more harm than good. I had gone through all of that [cancer treatment] and now I was self-destructing, you know I mean even my friends told me. He said to me, you passed 1 year, you passed through that, you were strong, you were confident and then after three years and a half you are cured and you start doing... you are killing yourself. I'm going to be honest (I used) a bit of drugs, a bit of alcohol and the type of recourse that people use sometimes to forget.

In terms of distress, disturbed mood was still present for some survivors; some had thoughts of death and one said that he would rather die than go back through cancer-treatment. In our analysis of all distress symptoms reported from the period of diagnosis to the long-term survivorship, we found other psychological reactions reported less often. Throughout the experience some survivors felt concern about changes in body image, sexual functioning and identity. Some reported loss of self-esteem, loss of masculinity, anger, and worry about the repercussions of the cancer diagnosis on loved ones. Additionally, mental fatigue, boredom during treatment and anticipatory nausea during the treatment period were mentioned. Finally, some survivors also voiced worries related to possible infertility at the various stages of the cancer experience (see: Robitaille et al., under revision). Despite the hardships of cancer, the presence of PTSD and distress symptoms, many survivors specifically reported a good general adaptation in the long-term post-treatment phase.

Coping

Most survivors were eager to discuss their coping mechanisms. While not central to this study, these descriptions help to further elaborate the relationships among PTSD, distress and posttraumatic growth. During the interviews and analysis of results it became apparent that all survivors were inclined to share how they naturally coped with cancer and how, for most, their lives were changed for the better after its treatment. Survivors reported that they used various coping strategies. The most often reported coping mechanism was optimism. Nearly every survivor interviewed said that keeping a positive spirit from the moment of diagnosis helped them to cope with the cancer experience. There were many participants who recalled being self-confident and focusing on positive future plans. Also, a number of survivors said that the reassurance provided by their

health care professional about the prognosis of their disease helped them to stay optimistic:

> Yeah it's a mental combat to keep my moral up and maintain hope to not let yourself go into self-pity. That's the worse thing you can do, and not just for cancer, for anything really. It applies to life in general.

Survivors also coped actively by seeking social support and by keeping busy. Survivors said that talking about the experience to others helped them cope, and were grateful for having received good support from family, friends or health care professionals. In contrast, some survivors tried to keep a strong front in public and tried not to let others see that they experienced distress. In many instances, this theme resembled strongly the issue of avoidance of reminders of the illness already presented under the rubric of PTSD symptoms:

> I think I am able to control it rather well, and I'm not a very emotional person. I don't show it too much, I try not to show, especially when I had guests, and these things... I kept them for myself I think. And when the people left, when I was alone sometimes I found it hard, because it was then that it would hit me and I knew there was no one around so I didn't need to be strong. I didn't need to show them that I was able to make it, I was alone. It was harder I think because then I would let go.

Staying busy and trying to maintain a "normal" life helped a quantity of survivors cope. These survivors said they kept going to work, maintained some social activities and exercised while they were cancer patients. Survivors described other coping strategies such as seeking professional help in counseling, acceptance of the disease, active information seeking about the disease, and some coped with a good sense of humor:

> So you cope with humor also a little bit? Survivor: Yeah...like a lot of the time people used to ask me like...how come your hair is so short and you don't have eyelashes and eyebrows so I say yeah I swim a lot, so I'm on the swimming team.

Also because there are well known personalities who were diagnosed with either testicular or lymphatic cancer, some survivors reported they compared themselves to the experiences of these men:

> Look at Mario Lemieux, he had Hodgkin's disease, he kept playing...he missed sometime, but he never lost all of his hair, he kept playing (...) Lance Armstrong had testicular, but he also had it in the brain too didn't he (...) and Saku Koivu his was Non-Hodgkin's and what he had made what I had look like a bad cold.

Posttraumatic growth

One of the strongest emerging themes from the interviews was that of posttraumatic growth, almost all of the survivors reported that the cancer experience had brought positive benefit for them. More specifically, participants said they experienced a positive change in personality. They reported feeling more mature, more sensitive, more empathy for human suffering and feeling like a stronger person. Additionally, some of these participants said they had a greater appreciation for life, and had reevaluated their life priorities so that they did not let themselves get upset so much for trivialities anymore. One survivor also mentioned he now took more time for himself since the cancer experience:

> It is when health is threatened that we realize its value, its true value. Also, to appreciate the good times, life's little happinesses, it's not the quest for something ultimate... it's the sum of little things. Also being more aware of others' hardships.

The cancer experience also strengthened some relationships and made survivors reevaluate who their real friends were:

> It was a test, but it absolutely strengthened our relationship, especially going through the chemotherapy... such as the vomiting, the whole hospital ordeal . . . My wife was always there and very supportive and would be leaving work to be with me. A lot of times I even said, don't worry about it, you can go to work, but she wouldn't hear of it, so that helped a lot and I think that brought us to another level, it strengthened our bond.

Creating strong positive relations with others became more important and one survivor even offered to become a mentor for others faced with the same cancer as him:

> Like myself, I gave my name (to the hospital) so that if ever someone had the same cancer as me and they think it would be helpful that I talk to him, well you call me, and anytime I will go because I think that that is important."

In sum, the suddenness of the cancer diagnosis for young individuals may leave them unprepared to deal with cancer and the side-effects of its treatment, as well as the appearance of distress symptoms and PTSD. However, in the survival phase, the quality of the experience is not completely negative, as clearly many report positive outcomes.

Discussion

This study explored the cancer-related symptoms of PTSD and distress (specifically symptoms of depression and anxiety), and reported on the coping and posttraumatic growth experienced by survivors. The results from this study are consistent with the social-cognitive transition model of adjustment (Brennan, 2001) and the literature on posttraumatic growth (Tedeschi & Calhoun, 2004).

Adjustment to cancer is a process of transition as individuals attempt to integrate and learn from the changes precipitated by their illness (Brennan, 2001). The social-cognitive transition model of adjustment (SCT) (Brennan, 2001) is a normative model of adjustment that integrates the paradox of contradictory outcomes: it accounts for both the presence of a high degree of distress as well as the presence of posttraumatic growth. The SCT model, drawing upon social-cognitive, coping and traumatic stress theories, posits that humans learn from cumulative experiences throughout their lives and develop an assumptive world composed of abstract schematic representations of themselves, the social and physical world (Brennan, 2001; Janoff-Bulman, 1992). These assumptions allow individuals to make some predictions about their environment and also provide a motivational structure for a person's life. When presented with new information individuals will either assimilate the information in their existing assumptions (strengthening of assumptions) or modify their existing assumptions in order to accommodate the new information (elaboration or expansion of assumptions) (Brennan, 2001; Piaget, 1952). While early manifestations of PTSD symptoms are common following traumatic events, the development of the full syndrome is only present in a minority of individuals (Brennan, 2001; Kessler, 2000; Tedeschi & Calhoun, 2004). People may respond differently in the face of traumatic events based on their differing models of the world and their different social conditions and their sociodemographic characteristics. A flexible assumptive world allows for a gradual integration of novel information, while individuals who hold inflexible models and who suppress mismatched information may be more vulnerable to develop long-lasting PTSD symptoms.

When faced with a life-threatening diagnosis such as cancer, the capacity of the assumptive world to process the information, to make predictions and to react adaptively

may be overwhelmed. In our study, the cancer diagnosis was a shock for many of the participants, a finding that matches what has been reported in the literature (Brodsky, 1999, Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). Survivors recalled a sense of helplessness and fear following diagnosis, their appraisal matching the definition of a traumatic stressor. A study has found that the severity of the disease (indicated by disease stage and number of treatments received) was not related to appraisals of breast cancer meeting the stressor criteria for PTSD (Cordova et al., 2001), evidence that individual appraisals of the situation are in fact more important than the severity of the event itself. In this study, survivors reported a strong sense of fear and uncertainty about the future as well as a fear of death. Some had some anxious thoughts, anticipated the future with worry and many reported a state of denial after diagnosis. However, for some, the diagnosis was quickly reappraised as a challenge as patients were reassured by physicians. Early positive reappraisal of the trauma may be a factor that leads to a timely return to homeostasis following a cancer diagnosis. Positive appraisals and reappraisals of a traumatic event may protect against developing PTSD (Olff, Langeland, Draijer, & Gersons, 2007). Positive reappraisals have been linked to faster cortisol habituation to subsequent stressors, indicating a greater flexibility in the system (Epel, McEwen, & Ickovics, 1998).

Avoidance and denial may be part of the normal adaptive process that preserves a coherent mental model of the world, while defending against threatening and painful information that cannot be easily integrated into the assumptive world (Brennan, 2001; Horowitz, 1986). Immediately after the diagnosis, patients reported denial, avoidance and a blunted emotional reaction. These reactions may serve as a protective function and may or may not be reflective of underlying distress. At the time of diagnosis, the many

implications of cancer need to be absorbed. In the initial period following diagnosis, avoidance adaptively protects the individual from the overwhelming nature of this stressful experience. However, the competing psychological need to assimilate the new information into the existing assumptive world may lead to manifestations of intrusions, rumination and reexperiencing. Consequently, co-existing manifestations of avoidance and intrusions are opposed parts of the regulation of information absorption (a process particularly notable in the long-term survivorship phase of this study). In this study, the intrusive thoughts reported at diagnosis and treatment strongly resembled anxious worries about the future threats while intrusions reflecting past experience only appeared post-treatment. The results presented in this study illustrate the many anxious worries about the future that patients experience: the fear of death, the unknown nature of treatments, possible complications and side-effects. These anxious worries resemble the intrusive symptoms of PTSD, but they are related to preparing oneself to respond to a future threat rather than the recurrent thoughts about a past trauma as is more typical of PTSD. As mentioned elsewhere (Mundy & Baum, 2004), the worries in patients diagnosed with a life-threatening illness may be more future-oriented than focused on the past. In our study it is only in the long-term survival phase that intrusions made their appearance, earlier observations may be more characteristic of anxiety.

When patients were receiving chemotherapy treatments, depressed mood was increasingly reported and with greater intensity. This was the only time when patients felt despair with a sense of discouragement, which was at times accompanied by thoughts of death. Being unable to enjoy usual activities like others, the demanding treatments, boredom, nausea and fatigue were precipitating factors for depressed mood and anger. This period of emotional turmoil and intensive hardship may force individuals to revisit

long-held assumptions. Specifically, life trajectory and life goals may be threatened as patients start to envision their death and are also faced with physical limitations. Life as a cancer patient revolves around treatment rituals and there is a possibility that the patients develop maladaptive assumptions about their life-trajectory such as feelings of despair and a sense of foreshortened future. In our study, some survivors mentioned how their existing assumptions about the rational and moral nature of their lives were challenged. Assumptions about the self and self-worth, and the sense of control over the world are also challenged during the treatment period. Body-image issues, loss of masculinity and loss of self-esteem were themes mentioned by participants which replicates earlier findings (Green, Galvin, & Horne, 2003); also the potential for infertility in the aftermath of cancer may force individuals to revisit important assumptions and life goals (Robitaille et al., under revision).

In the post-treatment phase, many survivors reported a generally good adjustment and posttraumatic growth. However, this period was by no means devoid of distress, more survivors reported the presence of PTSD symptoms, such as high intrusions, avoidance, hypervigilance and emotional numbing. It has been suggested elsewhere that trauma occurs following the cancer experience because during treatment all the energy is centered on healing (Brodsky, 1995). In the post-treatment period, avoidance was salient for many patients, as well as other signs of distress. There is a potential for maladaptive assumptions to emerge, enduring distress and when symptoms persist they become problematic for survivors. In our study, some participants experienced problematic alcohol and drug use, and some mentioned a delayed emotional reaction. The end of treatment phase is described as difficult as survivors experienced a loss of support and loss of special attention from medical staff and social networks. The reality of life after

cancer may be distinct from that of before the cancer. The uncertainty about a possible recurrence may prompt hypervigilance and lead to an increase in intrusive symptoms. The fear of recurrence contributes to maintaining the perception of a sense of current threat post cancer treatments and encourages a belief that the trauma is not time-limited as discussed by the cognitive model of Ehlers and Clark (2000). Fear of recurrence has been shown to be positively related to PTSD symptoms in a sample of lymphatic cancer survivors (Black & White, 2005).

While assumptions are being shattered, they may also be replaced by other adaptive schemas, which produce posttraumatic growth. For growth to take place, the trauma has to be challenging enough to put into question the way that the person understands the world and this implies a change in this understanding. Thus, there is a large potential for growth as the person integrates the new reality of trauma in the assumptive world through the inclusion of new assumptions and the exclusions of old ones. Nonetheless, the relation between distress and posttraumatic growth is tenuous. The distress and pain triggered from the traumatic event are not seen as positive outcomes and the crisis is not itself seen as desirable even in the event of posttraumatic growth. It is important to recognize that posttraumatic growth and distress are not mutually exclusive and often co-occur, and one may not be a necessary condition for the other. In a sample of breast cancer patients, Cordova (2001) found that posttraumatic growth scores were not related to scores of PTSD or depression, nor was posttraumatic growth related to greater well-being.

The coping processes taking place also influence the cognitive integration of trauma and the extent of posttraumatic growth. For example, the opportunity to talk about the experience of cancer and the presence of social support may be beneficial to cognitive

processing and may help through the provision of alternate schemas (Tedeschi & Calhoun, 2004). In contrast, individuals who are remarkable in hardiness possess a high sense of coherence and who are highly resilient, may not be challenged sufficiently by the traumatic event to enter a process of revaluation of existing schemas (Tedeschi & Calhoun, 2004). In our study, some survivors mentioned coping by staying active, which might reflect an attempt to preserve assumptions about the self. In contrast, personality characteristics such as optimism, extraversion and openness to experiences, which allows for a flexible re-evaluation of assumptions, may make posttraumatic growth more likely (Tedeschi & Calhoun, 2004). In two distinct prospective studies of breast cancer patient investigators found that optimism as measured in the initial interview was inversely and strongly related to distress at each time point (Carver et al., 1993; Epping-Jordan et al., 1999). Coping by optimism may take place mostly at the beginning and through treatments and if there is a chronology of posttraumatic growth. It does not seem to occur straight after the event, but rather as lesson learned from the experience and whether it endures many years post-completion of treatments is an issue that remains to be investigated.

Limitations

The results of this qualitative study may not generalize to other cancer populations of young males, to female cancer patients, or to older patients. In addition, the use of a convenience sample may have biased results by attracting participants who were most interested or who had more symptoms. Generalizations are also restricted by the large amount of time elapsed between the diagnosis and data collection (6.3 years) which may have lead to a bias in recall about psychological reactions at that time. Future research on the presence of the sub-syndromal and the full-syndrome of PTSD is needed through

longitudinal and prospective quantitative studies. These studies could identify sub-groups of patients who are more at risk of developing pathological responses and inform health care professionals concerning the manner to direct limited resources towards helping these patients. As other authors have noted, the relationship between distress and posttraumatic growth is unclear (Tedeschi & Calhoun, 2004); it may be associated with less distress in some studies or show no apparent relation to one another. This association needs to be clarified.

Conclusions

In the initial stage following the diagnosis, survivors are living a period of intense shock and distress. They also report that the medical journey ahead of them is frightening and report some experience of anxiety. Avoidance and denial are common initial reactions. It would be appropriate to recommend that the large amount of information presented to patients be repeated several times by the many professionals that encounter each patient. Several repetitions may alleviate some of the stress associated with the unfamiliar processes that will order their lives for the months ahead; when the initial diagnosis is reappraised as something manageable; a challenge over which one can exercise some control, and therefore patients may be less likely to experience PTSD symptoms. The results of our study suggest that patients are under a significant amount of emotional duress especially during the treatment phase. Patient's initial concerns often carry over through the treatments and post-treatment phase. Furthermore, additional support (social, emotional and practical) is important at the end of treatment, where new psychological challenges may appear. Clinical interventions might be an important source of support for patients in this stage.

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Table

Table 1
Summary of PTSD, distress, coping and PTG: transitions through the cancer experience

Diagnosis phase	Treatment phase	Long-term survival
Appraisals • Shock very common • Fear of death, foreshortened future • Helplessness and horror • Quickly reassured about a good prognosis by the health care professional: threat being reappraised as a challenge • Existential questioning	**Appraisals** • Shock receding, less frequent, present in one individual • Fear of the future, treatments • Cognitive processing of cancer experience beginnings	**Appraisals** • Delayed emotional reaction • Cognitive processing of the cancer experience • Fear of recurrence • Loss of medical support and attention: fear of recurrence: appraisals of the trauma that maintain a sense of current threat need to be modified.
PTSD Symptoms: • Anxious anticipation : intrusive thoughts rare • Fear about the future and the unknown process of cancer treatments • Denial (unconscious-related to shock) • Avoidance • Numbing • Depersonalization • Nightmares	**PTSD Symptoms:** • Anxious anticipation : intrusive thoughts rare • Fear about the future and the unknown process of cancer treatments • Avoidance becoming more frequent • Denial • Nightmares • Hypervigilance	**PTSD Symptoms:** • Intrusive thoughts most frequent in this phase • Fear about recurrence • Fear of secondary impact on their lives • Avoidance most frequent in this phase • Numbing • Hypervigilance • Trouble remembering important parts of the experience • Sense of foreshortened future
Distress: Anxiety : apprehensions about the future Depressed Mood • sadness	**Distress:** Anxiety important in a wide-range of areas concerning treatment Depressed Mood • Suicidal thoughts /thoughts of death • Despair	**Distress:** Anxiety important in a wide range of areas concerning survival. Depressed Mood Drug abuse/self-destructive behavior
Other distress symptoms reported through all phases: change in body image, loss of self-esteem, anger, fatigue, boredom, anticipatory nausea, worries about the possibility of infertility, being cut off from regular activities		
Coping • Optimism • Early acceptance • Confident, focusing on future plans • Maintaining a regular activity level • Seeking social support-emotional support • Keeping a strong front	**Coping** • Optimism • Acceptance • Maintaining a regular activity level • Seeking social support-emotional support • Active information seeking • Humor • Comparison to others • Consulting a professional • Keeping a strong front	**Coping** • Late acceptance • Optimism • Seeking social support-emotional support • Humor • Comparison to others • Consulting a professional • Keeping a strong front
Posttraumatic growth Not yet in effect	**Posttraumatic growth** • Closer bonds with family and friends; reevaluating social ties	**Posttraumatic growth** General good adaptation, feelings of having moved on from the experience • Change in identity for the better (feeling more mature, more sensitive, a stronger person, more compassionate) • More appreciation of life • Taking more time for one self • Revaluation of priorities in life (less stress for trivial things, • Closer bonds with family and friends

SECTION 3: SYMPTOMS OF PTSD IN YOUNG MALES RECENTLY DIAGNOSED WITH CANCER

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Abstract

Testicular and lymphatic cancers (Hodgkin's and non-Hodgkin's disease) are among the most common cancers in young males aged 18 to 45. It has recently been acknowledged that symptoms of posttraumatic stress disorder (PTSD) may be present following a cancer diagnosis, with incidence varying between 1.9% to 35.1% (Kangas, Henry & Bryant, 2002). Few studies have investigated the emergence of these symptoms longitudinally in the first year following diagnosis. This study investigates early manifestations of PTSD symptoms, the course of symptoms over 12 months and their predictors in a sample of patients with cancer as compared to a group of healthy controls. Methods: Newly diagnosed cancer patients (n=92), and community controls (n=88) were recruited. Participants were assessed on measures of PTSD, depression, anxiety, perceived stress and quality of life at diagnosis, 3 months, 6 months, and 12 months post-diagnosis. Results: Severe PTSD symptoms were observed in 3.4% to 8.3% of cancer patients on the PTSD Checklist-Civilian Version (PCL-C) and in 7% to 14.3% on the Impact of Event Scale (IES) over the four assessment points in the first year following diagnosis, compared with 1.5% to 3.9% on the PCL-C and 1.3% to 5.7% on the IES for controls. Repeated measure analyses of variance (ANOVAs) revealed that cancer patients had higher levels of PTSD symptoms, at time 2 and 4 on the IES, at times 2, 3 and 4 on the PCL-C, at time 2 for depression, and at times 1 and 2 for anxiety than controls, but were not different in perceived stress, nor in quality of life. Furthermore, there was a significant increase in PTSD symptoms over time. Initial scores of PTSD were the only significant predictor of PTSD at time 4. Conclusion: This study pointed to the pervasiveness of early PTSD symptoms and revealed an increase in PTSD symptoms for cancer patient between 6 and 12 months.

Introduction

In persons diagnosed with cancer, 35% to 45% of patients suffer from elevated levels of distress at some point during their cancer trajectory that may require intervention (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Given that posttraumatic stress disorder (PTSD) is highly comorbid with depression, anxiety and other types of distress (Amir & Ramati, 2002; Deimling, Kahana, Bowman, & Schaefer, 2002; Edgar, Rosberger, & Nowlis, 1992; Epping-Jordan et al., 1999, Haber et al., 2002; Kessler, Borges, & Walters, 1999) symptoms of this disorder are likely to be elevated in young males with cancer.

The objectives of this study are to determine the frequency of cancer-related PTSD symptoms in young male cancer patients, to understand how symptoms of cancer-related PTSD evolved in the first year following cancer diagnosis and to identify risk factors which are predictive of PTSD symptoms

For trauma most stressors are acute. The nature of a cancer diagnosis as a traumatic event involves both acute and chronic stressors (diagnosis, surgery, repeated chemotherapy and/or radiation therapy, side-effects, delayed effects, follow-ups, risk of recurrence and the long-term survivorship period). Since the recognition by DSM-IV (American Psychiatric Association [APA], 1994) that life-threatening illnesses, such as cancer, could be of sufficient magnitude to meet the criteria of a traumatic stressor, a number of investigations of PTSD symptoms in cancer patients have been conducted (Andrykowski, Cordova, Studts, & Miller, 1998; Epping-Jordan et al., 1999; Kangas, Henry & Bryant, 2002; 2005a). This literature indicates that cancer is often experienced by patients with shock, fear and helplessness (Brodsky, 1999; Robitaille, Rosberger, & Achille, 2008 under review). However, most prior studies of PTSD outcomes in cancer

patients or survivors have relied on cross-sectional designs (Andrykowski et al., 1998; Butler, Koopman, Classen, & Spiegel, 1999; Cella & Tross, 1986; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Fleer et al., in press; Kaasa et al., 1993; Kornblith et al., 1992; Palmer, Kagee, Coyne, & DeMichele, 2004) and none have compared the outcomes of patients to a control group, despite the fact that lifetime exposure to a qualifying traumatic event in the general population has been assessed to be within the range of 40% to 89 % in epidemiological studies (Breslau, Davis, & Petersen, 1991; Green, 1994; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Norris, 1992). Furthermore, few have explored the course of development of PTSD symptoms longitudinally. In a series of papers drawn from a single prospective study (Kangas et al., 2005a; 2005b; 2005c; 2005d), there was significant decline in PTSD symptoms from diagnosis to 1 year post-diagnosis, and none of those that had low acute stress disorder[2] scores at diagnosis developed PTSD at 1 year, pointing to the importance of an early assessment of PTSD symptoms following cancer diagnosis. However, this study used a mixed cancer sample (head and neck cancer and lung cancer) and also showed that there were significantly more women (47% and 42%) than men (13% and 5%) who met the criteria for a PTSD diagnosis at 6 and 12 months (Kangas et al., 2005a, 2005b). Other prospective studies pointed to a decline in PTSD symptoms in general (Manuel, Roth, Keefe, & Brantley, 1987) or in intrusions (i.e.: cognitive and affective reexperiencing of the traumatic event) but not in avoidance (i.e.: avoidance of trauma-related reminders and feelings) after diagnosis (Epping-Jordan et al., 1999). The few studies described above have used mixed gender samples or female-only samples; none have investigated PTSD

[2] Acute Stress Disorder is a diagnosis that applies to individuals having been exposed to a traumatic event and who exhibit symptoms for a period of two days to four weeks following the event. A PTSD diagnosis cannot be given to patients until they have exhibited symptoms of the disorder for at least 1 month.

longitudinally in males. The higher risk of PTSD in women is one of the most consistent findings in the epidemiology of posttraumatic stress disorder (Olff, Langeland, Draijer & Gersons, 2007). Women are twice as likely as men to develop PTSD in their lifetimes (10.4% vs 5%) even though men are more likely to be exposed to traumatic events in their lifetime (Kessler et al., 1995). PTSD symptoms following cancer have been measured in older women (mostly breast cancer patients) but not in younger men. Testicular cancer and lymphatic cancers are among the most common types of malignancies in men aged 45 or younger (Canadian Cancer Statistics/National Cancer Institute of Canada [CCS/NCIC], 2002; Trask, Paterson, Fardig, & Smith, 2003). Hence, the diagnosis comes at a time when males are concerned with finishing their studies, focusing on their careers, getting married and building a family, but when it is generally unexpected developmentally to be facing cancer.

There are no reports about the early development of PTSD symptoms and distress for young testicular and lymphatic cancer patients, or about the evolution of these symptoms during the first year following diagnosis. Low incidence rates of these diagnoses are a challenge to longitudinal studies. The National Cancer Institute of Canada (CCS/NCIC, 2008) estimates that there will be 890 new cases of testis cancer in 2008, 3800 new cases of Non-Hodgkin's lymphoma and 480 new cases of Hodgkin's lymphoma in males of all ages. Incidence rates are low, but have been steadily increasing in recent years. These disorders reach a peak incidence for males between the ages of 18 to 40, share comparable chemotherapy regimens (side-effect profiles, chemotherapy drugs used, potential for infertility post-chemotherapy), and all three have relatively good prognoses (Fossa & Dahl, 2002; Kaasa, Aass, Mastekaasa, Lund, & Fossa, 1991; Raemarkers et al., 2002, CCS/NCIC, 2008).

In general, younger age, past traumatic exposure, and prolonged or inescapable traumatic events constitute risk factors for PTSD (Herman, 1992). Lower age is related to increased symptoms of intrusions (i.e.: persistent and uncontrollable thoughts about the event, recurrent dreams about the event, physiological and emotional arousal upon cues resembling the event) and avoidance (efforts to avoid thoughts, feelings, conversations, places, and activities associated with the event, incapacity to recall important aspects of the event) in long-term breast cancer survivors (Butler et al., 1999) as well as newly diagnosed breast cancer patients (Epping-Jordan et al., 1999). Other variables such as lower education (Cordova, Andrykowski, Kenady, McGrath, Sloan, & Redd, 1995; Epping-Jordan et al., 1999) and lower income (Cordova et al., 1995) are also associated with an increased presence of PTSD symptoms in breast cancer patients. Key studies to date have failed to demonstrate significant relation between medical variables, such as disease stage or total number of treatments received and subsequent PTSD (Cordova et al., 2001; Kangas et al., 2005a, 2005b).

Rationale

The present study is the first longitudinal study of cancer-related PTSD symptoms to compare outcomes in young male cancer patients with that of a healthy control group. This study aims to identify the frequency, risk factors, and evolution of the PTSD symptoms. Psychological morbidity will be assessed to gain an understanding of the relationship between PTSD, depression and anxiety in these patients.

Hypotheses

It is hypothesized that: a) incidence rates of PTSD symptoms will be higher in cancer patients than in the control group, b) initial levels of PTSD symptoms will highly predict subsequent levels of PTSD symptoms, c) the highest level of PTSD symptoms in

patients will be at the time of diagnosis and will steadily decrease over time, d) younger age, prior history of trauma, lower education level and lower socioeconomic status will increase the likelihood of PTSD symptoms, and e) PTSD will be highly correlated with depression and anxiety.

Methods

Participants

Two groups of subjects were recruited: cancer patients (newly diagnosed with testicular, Hodgkin's, or non Hodgkin's lymphatic cancer) and healthy controls (healthy community volunteers and patients recruited at a fertility clinic). Ethics approval was obtained by the McGill University Institutional Review Board prior to the beginning of the study. Recruitment of newly diagnosed patients took place in hospitals in the Montreal area (Royal Victoria Hospital, Charles-Lemoyne Hospital, Jewish General Hospital-SMBD, Montreal General Hospital). Patients received written information about the study from their doctor, and those who expressed interest were contacted by the research coordinator prior to the initiation of chemotherapy treatments. Inclusion criteria for the patient sample of the study included : a) being between 18 and 45 years of age; b) having a sufficient physical and psychological health status to answer the questionnaires; c) receiving chemotherapy for the first time; d) having no history of a previous malignant tumor; e) having no history of radiotherapy. The healthy controls and infertile but otherwise healthy aged-matched controls (who had no history of cancer) were recruited through advertisement in local newspapers, and in a fertility clinic in Montreal.

Study design and procedures

Participants completed questionnaires and were interviewed at the following time points: time 1: just after diagnosis (and prior to the initiation of chemotherapy); time 2: 3

months post-diagnosis; time 3: 6 months post-diagnosis; time 4: 1 year post-diagnosis. Participants answered questionnaires in the presence of a trained interviewer available to answer questions at all time points except for time 2. Time 2 is a measurement time that was added to the original protocol and started some months after the beginning of recruitment; hence some of the first participants did not receive time 2. At time 2 patients were contacted by telephone because it was the only time point that did not coincide with regular medical follow-ups. Telephone surveys using standardized scales have been used to assess mental health in primary care research and they have proven to be a cost-effective mode of data gathering. There is a generally good agreement between data gathered by face-to-face interviews and that gathered by telephone interviews (Evans, Kessler, Lewis, Peters, & Sharp, 2004), and they have been found to be a valid method for measuring PTSD (Andrykowski et al., 1998). Sociodemographic data regarding age, income, education, marital status, employment status and number of children was collected at time 1.

Measures

Posttraumatic Stress Disorder. The Impact of Events Scale (IES) is a 15-item self-report questionnaire measuring the presence of intrusions (7 items) (i.e.: cognitive and affective reexperiencing of the traumatic event) and avoidance (8 items) (i.e.: avoidance of trauma-related memories and feelings) over the past 7 days. Separate scores may be calculated for these two scales, and they may be summed for a total score. Norms for both the total score and the separate subscales have been published for other cancer populations and may be used for comparison. Scores range from 0 to 35 for the intrusion subscale, 0 to 40 for the avoidance subscale and 0 to 75 for the total IES. Although the IES is not a diagnostic tool, the IES total score has been used to define three levels of clinical

concern: a score below 9 as "low", 9 to 19 as "moderate", and over 19 as "high" (Horowitz, 1982; Johansen, Wahl, Eilertsen, Hanestad, & Weisaeth, 2006). However, recent studies have employed more stringent criteria in scoring the IES. A total IES score of 26 and above was the established PTSD caseness criterion employed in the present study and prior investigations (Corneil, 1995; Fleer et al., in press; Murphy, Randal, Pike, & Johnson, 1999; Violanti, Andrew, Burchfiel, Dorn, Hartley, & Miller, 2006). The scoring criteria employed by the present study is: below 9 as the absence of symptoms, 9-25 as a mild presence of symptoms, 26-43 moderate level of symptoms (warranting clinical concern, possible need for treatment, likely PTSD) and scores of 44 and above as a severe presence of symptoms (Violanti et al., 2006). The IES has a good convergent validity with the Clinician administered PTSD Scale (CAPS). It correlations $r=0.81$ $p<0.001$ with the endorsed symptoms on the CAPS and $r=0.78$ $p<0.001$ with the CAPS intensity score (Neal, Busuttil, Rollins, Herepath, Strike & Turnbull, 1994). Using a cut-off score of 35, the IES showed a sensitivity of 0.89, a specificity of .88, and a positive predictive value of .88 with the CAPS (Neal et al., 1994). The IES produced a misclassification error rate of 11.4% (Neal et al., 1994).

In this study, the scale showed high internal consistency as indicated by Cronbach alphas between .91 and .92 for the total scale, between .87 and .89 for the intrusion subscale, and between .83 and .85 for the avoidance subscale. The IES has limited content validity for PTSD as it does not assess symptoms of hyperarousal (criterion D), does not cover some avoidant symptoms and some intrusive symptoms (Joseph, 2000). It remains one of the most widely used self-report measures of traumatic stress (Joseph, 2000), but another measure of PTSD symptoms was also included in the study which palliates to some of the IES weaknesses.

The PTSD Checklist- Civilian (PCL-C) has good face validity and content validity as it assesses the presence of 17 symptoms each corresponding to the specific symptoms of PTSD according to the DSM-IV (APA, 1994). It measures intrusions, avoidance, hypervigilance and numbing in the past month. The scoring used was the cut-off method: a score of 50 and above constitutes a clinical PTSD level, a score of 40 and above constitutes a partial PTSD (Andrykowski et al., 1998; Ruggerio, Del Ben, Scotti, & Rabalais, 2003). The PCL-C has good convergent validity with the Structured Clinical Interview for DSM-V- PTSD (SCID-PTSD) (Andrykowsky et al. 1998). Using a cut-off score of 50 and above, the PCL-C showed a sensitivity of 0.60 (with two false negatives; making it more likely that people with the disorder were not identified), a specificity of 0.99, a positive predictive power of 0.75 and a negative predictive power of 0.97. The diagnostic efficacy of the PCL-C in that study was 0.96 (Andrykowsky et al. 1998). In the current study, the scale showed high internal consistency as indicated by Cronbach alphas between .91 and .94 for the total scale. Both the IES and PCL-C are frequently used in studies of cancerous populations (Andrykowski et al., 1998; Butler et al., 1999; Cordova et al., 1995; Epping-Jordan et al., 1999), and have demonstrated uniformly high internal consistency. Patients answered the questionnaires measuring posttraumatic reactions by referring to their cancer experience, infertile controls referred to their experience of infertility and the healthy controls were asked to refer to their most stressful life event and to indicate the date at which the event occurred.

Distress. The Symptom Checklist-90 (SCL-90) was used to measure distress, specifically depression and anxiety. The instrument is composed of 9 subscales and allows for the calculation of a total general severity index (Derogatis, 1977, 1994; Derogatis & Savitz, 1999). Total scores are transformed into t-scores based on a normative sample of males,

according to the guidelines provided in the scoring manual of the instrument (Derogatis, 1994). Internal consistency was high in the present study with Cronbach alpha's varying between .97 to .98 for the total scale, from .86 to .93 for the depression subscale and from .83 to .89 for the anxiety subscale. This scale has also been previously used in samples of cancer patients (Amir & Ramati, 2002; Epping-Jordan et al., 1999).

Perceived Stress. The Perceived Stress Scale (PSS) was used to assess perceived stress. It is a 14-item scale designed to measure the degrees by which situations in one's life are appraised as stressful (Cohen, Kamarck, & Mermelstein, 1983). Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The scale also includes a number of direct queries about current levels of experienced stress. Moreover, the questions are of a general nature and hence are relatively free of content specific to any sub-population group. The questions in the PSS ask about feelings and thoughts during the last month *(i.e.: In the last month, how often have you been upset because of something that happened unexpectedly?).* In the present study, internal consistency varied from .80 to .86.

Quality of life. The Functional Assessment of Cancer Therapy-General (FACT-G) is a scale that measures health-related quality of life along four subscales dimensions: physical, social and familial, emotional and functional well-being (Cella et al., 1993). The scale contains 27 items for cancer patients and 21 items for the general population because 6 items address issues specific to illness (Brucker, Yost, Cashy, Webster, & Cella, 2005). Subscales are prorated according to the number of items answered and the number of items on the scale [(Sum of item score) x (N of items on the scale)]/N of item answered. The scale showed high internal consistency with Cronbach alphas ranging from .86 to .91.

History of trauma. Because a prior history of trauma may constitute a risk factor for the development of PTSD at an ulterior moment it is important to control for its presence. Trauma history was assessed at time 1 with a question derived from criterion A1 for PTSD of the DSM-IV (APA, 1994) (hereafter referred to as trauma history). The item read:

> *Have you ever lived, been witness, or have been confronted to a stressful event where you could have been seriously injured, threatened of death or where there was danger for your physical integrity or that of another? (The event you lived/witnessed is? The date of this event is?)*

The decisional criterion was that of being an event that could expose the participant to potential death or physical harm (see appendix 1 for a complete list of reported events coded as traumatic vs. non-traumatic). This variable was dichotomized and scored as present or absent.

Stressful life events. The Social Readjustment Rating Scale (SRRS) (Holmes & Rahe, 1967; Scully, Tosi, & Banning, 2000) is the most often used measure of stressful life events. The SRRS consists of 43 life events, commonly reported as stressful identified from clinical psychological experiences (Holmes & Rahe, 1967). These items share the similarity of being events that require a certain level of adjustment from one steady state to another, regardless of the desirability of the event. Nonetheless, items respect the logic that uncontrollable and undesired event will generate a greater stress response than controllable and desired event (Scully et al., 2000). Items include events about family, marriage, occupation, finances, residence, social relations, education, religion, recreation and health (Holmes & Rahe, 1967). The original scale represented a range of typical life events classified from most to least stressful in terms of what was historically appropriate

in the late 60s. This study employed the revised scale (with items differently weighed and formulated) proposed by Scully and Tosi (2000) and measured stressful life-events in the past year at time 4. Higher scores indicate more probability of stress related illness (Holmes & Rahe, 1967).

Findings

Sample Characteristics

The final sample consisted of 180 subjects. The cancer group consisted of 48 testicular cancer, 29 Hodgkin's Lymphoma, and 15 non-Hodgkin's Lymphoma patients (total n = 92). Because prognosis, age group, treatments received and side-effects in these patients with cancer are very similar (CCS/NCIC, 2008) we decided to combine the groups to increase statistical power (Cohen, 1969, 1992). Independent sample t-tests were conducted to test the mean differences between testicular, Hodgkin's and non-Hodgkin's cancer patient on key measures (depression, anxiety, intrusions, total IES, PCL, age). No differences were found between groups on any of theses measures except for the avoidance subscale of the IES where the NHD group had higher avoidance than the HD $t(42) = -2.07$ $p<0.05$ at time 1 and than the TC $t(61) = -2.42$ $p<0.02$ at time 1, but not at any other time points. The control group consisted of 64 community controls and 24 infertile controls (total n=88). Comparisons were performed to test the mean differences between the community controls and infertile controls on key measures (depression, anxiety, intrusions, avoidance, total IES, PCL, age). No differences were found between the two groups on any of the measure, except for age $t(88)= -7.1$ $p<0.000$ (infertile controls being slightly older), at any of the time points. Another conceptual justification for the combination of the control groups is that the purpose of this study is to clarify how young men diagnosed with cancer experience symptoms of PTSD

compared to young men from the general community. The need for a sufficient statistical power in analyses (Cohen, 1969, 1992) was also a consideration in assembling the two groups in order to avoid false negatives (type II errors: failing to observe a difference when in truth there is one). Mean age of the sample was 27.1 (SD = 6.67), participants were primarily single (64.1%), non-parent (87.8%), had some university level education (64.1%) and employed full-time (44.1%) (See Table 1 for complete sociodemographic characteristics of sample). To examine potential differences between groups, sociodemographic variables were dichotomized. Marital status was divided into being married (or common law) versus being non-married; income was divided into less versus greater than $40 000 per year (median); education was divided into less than versus some university level education (64.5% of the sample had some university); parental status was divided into parent versus non parent, and employment was divided as employed (54.7% of the sample was working full or part-time) versus non-employed.

The motives for attrition and the detailed characteristics of those who missed a time point or dropped out before time 4 and those who completed all time points are presented in appendix 2. For the control group there was only one substantive difference between the drop-outs and those who completed 4 time points. Those who remained in the study were less likely to be married than those who missed a time point or dropped out X^2 (1, N= 87) = 4.949 p<0.026. For the cancer patients, there was no difference on all sociodemographic measures for those who remained versus those who-dropped out of the study. However, there was a significant difference on the IES scale and subscales. Those who dropped out of the study were likely to have higher scores in the IES total [t (90) =2.175, p<0.03], and on the intrusion subscale [t (90) =2.193, p<0.03], but not on the avoidance subscale [t (90) = 1.692, ns] at time 1.

T-tests and chi-squares were also conducted between the control and cancer groups regarding sociodemographic variables. There was no difference between groups in terms of marital status and age, but the controls had a slightly higher level of education X^2 (1, N= 180) =25.75 p<0.000 (dichotomized as university vs. no university) and the cancer group had a slightly higher income X^2 (1, N= 152) = 5.847 p<0.016 (dichotomized as 40000 or less vs. more than 40000), were more likely to be parents X^2 (1, N=179) = 3.308 p<0.069, and were more likely to be employed X^2 (1, N=178) = 3.725 p<0.05 (dichotomized as working full-time or part-time vs. non employed).

Preliminary analyses

The challenge of subject attrition over time was handled in a number of ways. In the longitudinal analyses, missing cases were handled by a pairwise deletion. However, even for those who completed each time point, there were occasionally some missing items on questionnaires (i.e. participant having missed a question on a particular scale). When no more than 15% of items were missing on a questionnaire, these items were replaced using the maximum-likelihood estimization maximization technique (Enders, 2003; Little & Rubin, 1989; Peugh & Enders, 2004), in no cases were complete cases replaced.

The longitudinal data was analyzed in two ways. In the first set of analyses, the final sample consisted of only the participants who completed every time point. In the repeated measure ANOVAs only the results representing the final sample are presented. The second set of analyses consisted of all of the patients available at each particular time point (hereafter called the cross-sectional sample). This dual approach to the analytic process maximizes the sample size for both the longitudinal and cross-sectional analyses

and allows for examination of convergence and divergence of the results that may have important clinical 'real world' implications.

PTSD symptoms: descriptive data

Of the total sample, 20.1% of the total sample (18.5% of cancer patients and 25.8% of the control group) reported having lived through or witnessed an event (in their lifetime) that could have caused serious injury or death to themselves or others (Table 2). The mean elapsed time since the event was 80.54 months and the range was 12 to 252 months (see appendix 1 for a list of reported events).

To observe levels of PTSD (none, mild, moderate, severe) symptoms per groups at each time point, frequency counts were performed (Table 3). Elevated scores (moderate to severe levels of symptoms) on the IES and PCL-C represent a proxy for likely PTSD cases. An examination of response frequencies in the cross-sectional sample on the IES revealed moderate to severe levels (score of 26 and above: likely PTSD caseness) of PTSD symptoms in 34.8% of cancer patients at time 1, 34.9% at time 2, 21.2% at time 3 and 24.5% at time 4. For the control groups, 20.5% had moderate to severe levels of PTSD at time 1, 15.6% at time 2, 17.9% at time 3, and 15.1% at time 4. The responses on the PCL-C revealed moderate to severe (score of 40 and above: likely PTSD caseness) levels of PTSD symptoms in 13.6% of cancer patients at time 1, 22.2% at time 2, 16.6% at time 3 and 20.7% at time 4. For the control groups, 12.5% had moderate (subclinical) to severe levels of PTSD at time 1, 3.9% at time 2, 7.5% at time 4 and 9.1% at time 4. A complete list of traumatic (or stressful) events reported by control participants is available in appendix 3.

To verify whether initial PTSD caseness (moderate to severe score on the IES and PCL-C) had an influence on PTSD caseness at time 4, a series of chi-square analyses

were performed between those who had a likely initial PTSD caseness and those who did not (as dichotomized between high and low scores). For the final sample chi-squares revealed that 11 out of 37 (29.7%) cancer patients had likely PTSD at time 1 on the IES. Of those who had PTSD at time 1, 45.4% also had PTSD at time 2, X^2 (1, N = 37) = 5.25 p<0.02. Of those who had PTSD at time 1, 45.4% had PTSD at time 3, X^2 (1, N= 37) = 7.19 p<0.007; and 72.7% had PTSD at time 4, X^2 (1, N= 37) = 16.58 p<0.000; while 11.5%, 7.7%, and 7.7% of those who did not have PTSD at time 1 reached clinically significant levels of symptoms at time 2, 3 and 4 respectively. On the PCL-C, 5 out of 38 (13.2%) cancer patients had likely PTSD at time 1 on the PCL-C. Of those who had PTSD at time 1, 80% also had PTSD at time 2, X^2 (1, N= 38) = 17.85 p< 0.000; 80% had PTSD at time 3, X^2 (1, N= 38) = 17.85 p< 0.000; and 100% had PTSD at time 4, X^2 (1, N= 38) = 25.5 p< 0.000; while 6%, 6%, and 6% of those who did not have PTSD at time 1 reached clinically significant levels of symptoms at time 2, 3 and 4 respectively. For the final sample of control participants, 14 out of 61 (22.9%) had PTSD at time 1 on the IES. Of those who had PTSD at time 1, 50% had PTSD at time 2 X^2 (1, N= 61) = 14.97 p< 0.000; 64.2% had PTSD at time 3, X^2 (1, N= 61) = 26.29 p< 0.000; and 50% at time 4, X^2 (1, N= 61) = 17.95 p< 0.000; while 6.3%, 4.2% and 4.2% of those who did not have PTSD at time 1 reached clinically significant levels of symptoms at time 2, 3 and 4. On the PCL-C, 13.1% of control participants had PTSD at time 1. Of those who had PTSD at time 1, 25% also had PTSD at time 2, X^2 (1, N= 61) = 7.94 p< 0.005; 25% had PTSD at time 3, X^2 (1, N= 61) = 7.94 p< 0.005; and 25% at time 4, X^2 (1, N= 61) = 3.455 p< 0.063; while 1.8%, 1.8% and 5.6% of those who did not have PTSD at time 1 reached clinically significant levels at time 2, 3 and 4. The lower rates of moderate-to-severe PTSD symptoms in the control group are apparent when descriptive findings are

examined. As was predicted, the cancer patients had significantly greater PTSD symptom severity than the controls over time. Repeated measure ANOVAs were carried out to confirm these observed descriptive group differences.

Repeated measure ANOVAs (General linear model)

Impact of Events Scale

A repeated measure ANOVA for the total score of the IES scale resulted in significant results for the between group (cancer vs. control) effect $F(1, 96) = 4.46$ $p<0.04$ and the group X time interaction $F(3, 94) = 3.11$ $p<0.03$. The within-group effect of time was not significant.[3] Paired sample t-tests (between time 1 and 2, time 2 and 3, and time 3 and 4) were performed to examine at which time points significant differences emerged within each group and independent sample t-tests (between the cancer and control group at time 1, 2, 3, and 4) were performed to verify at which time point were the groups significantly different.

Paired sample t-tests for the cancer group revealed a significant difference between time 3 and time 4 on the IES total score, where the cancer group experienced a

[3]In order to test normality, skewness and kurtosis was verified for all scales at every time point. There were violations to the normality assumptions on the IES and PCL-C scales, with most violations being skewed to the left (low severity of symptoms), which is to be expected in a non-psychiatric population. Because of the greater facility to interpret and compare findings expressed in the original values of the scale, the original non log-transformed data was used in all analyses. In order to correct for non-normality, natural log transformations were performed on non-normal scales and results from log-transformed data will also be presented. Also, it has long been established that moderate violations of parametric assumptions (i.e. normality, homogeneity of variances, and interval level of measurement) have little or no effect on substantive conclusions in most instances (Cohen, 1969). Because of a concern for the normality of the distribution (on the IES and its subscales and on PCL-C), log transformations were additionally performed. Unlike the non-transformed data, the repeated measure ANOVA for the log-transformed IES produced a non-significant effect groups X time interaction. However, the within individual effect of time remained non-significant, while the between groups effect was still significant $F(1, 96) = 10.03$ $p<0.002$. In both analyses (transformed vs. non-transformed data) there was an overall difference between groups on the IES total score.

rise in IES scores t (36) = -2.0 $p<0.05$[4]. For the control group on the IES there was a significant difference decrease in IES scores from time 1 to time 2 t (60) = 2.586 $p<0.012$. Independent sample t-tests revealed that the cancer group had higher scores than the controls on the IES at time 2 t (96) = 2.54 $p<.013$ and at time 4 t (96) = 2.78 $p<0.007$. Mean IES total scores for the final sample at each time point are shown in Figure 1, Figure 2 represents the percentage of individuals (from the final sample) having elevated (moderate and severe levels) symptoms on the IES at every time point. Only the results for the final sample are presented in this paper, results for the repeated measure ANOVAs for the cross-sectional sample on all measures are presented in Appendix 4.

Intrusion and avoidance subscales of the IES

The repeated measure ANOVA for the intrusion subscale of the IES yielded a non-significant effect of group membership. There was a significant groups X time effect, F (3, 94) =3.58 $p<0.01$, but there was a marginally significant within-group effect of time F (3, 94) =2.56 $p<0.06$.[5] Paired sample t-tests for the cancer group revealed that there was a significant decrease in symptoms on the intrusion subscale of the IES from time 2 to time 3 t (36) =2.11 $p<.042$ and a significant increase in symptoms from time 3 to time 4 t (36) = -2.58 $p<.014$. For the control group on the intrusion subscale of the IES, there was a significant decrease in symptoms from time 1 to time 2 t (60) = 2.80 $p<0.007$. Independent sample t-tests revealed that the cancer group had higher scores than the

[4] If Bonferroni corrected alphas were used this would become marginally significant (Perneger, 1998; Sankoh, Huque, Dubey, 1997). The significance level would be $p<0.025$, $p<0.0167$ and $p<0.0125$ for analyses respectively holding 2, 3 or 4 sets of tests.

[5] The repeated measure ANOVA for the log transformed data on the intrusion subscale of the IES also produced very similar results. There was a significant effect for group membership F(1, 96) =8.04 $p<0.006$, and a significant effect for both the interaction of groups X time F(3, 94)=2.77, and the within individual effect of time F=2.64 (3, 94) $p<0.05$.

controls on the intrusion subscale at time 2 t (96) = 2.57 $p<0.012$ and time 4 t (96) = 2.25 $p<0.027$.

The repeated measure ANOVA for the avoidance subscale of the IES yielded only a significant effect for group membership F (1, 96) =5.08 $p<0.03$. The within group effect of time and the interaction effect of group X time were not significant.[6] Paired sample t-tests revealed that for both the cancer and the control group there was no significant change through time on the avoidance subscale of the IES. Independent sample t-tests revealed that the cancer group had higher scores than the controls on the avoidance subscale of the IES at time 2 t (96) = 2.07 $p<0.04$, time 3 t (96) = 1.9 $p<0.06$ and time 4 t (96) = 2.88 $p<0.005$.

PTSD Checklist-Civilian

The repeated measure ANOVA for the total PCL-C scale demonstrated significant effects of group membership F (1, 97) =6.20 $p<0.01$ and a significant effect for the interaction of groups X time F (3, 95) =3.21 $p<0.02$. There was no significant effect for the within-group effect of time.[7] Paired sample t-tests for the cancer group revealed there was a significant increase in symptoms on the PCL-C from time 1 to time 2 t (37) = -2.682 $p<0.011$, but no difference through time for the control group. Independent sample t-tests revealed that the cancer group had significantly higher scores than the controls on the PCL-C at time 2 t (38) = 6.20 $p<0.005$, at time 3 t (37) = 5.79 $p< 0.007$ and at time 4 t (38) = 4.62 $p<0.037$. Figure 3 shows the mean scores for the PCL-C for the final sample

[6] The repeated measure ANOVA for the log transformed data on the avoidance subscale of the IES produced the same results. Only the effect of group membership was significant F (3, 94) =7.27 $p<0.008$, and both the within individual effect of time and the interaction effect of groups X time were not significant

[7] The repeated measure ANOVA for the log transformed data on the PCL-C also produced a significant effect of group membership F (1, 96) = 8.18 $p<0.005$ and a significant effect for the interaction of groups X time F (3, 94) =5.01 $p<0.002$. However, with the log transformed data the within individual effect of time became significant F (3, 94) = 3.32 $p<0.02$.

and Figure 4 shows the percentage of individuals (from the final sample) having elevated (moderate and severe levels) symptoms on the PCL-C at every time point.

SCL-90 depression and anxiety

The repeated measure ANOVA for SCL-90 depression scale revealed a significant effect of group membership $F(1, 95) = 4.67$ $p<0.03$ and a significant interaction of groups X time $F(3, 93) = 3.77$ $p<0.01$. There was no significant effect for the within-group effect of time. Paired sample t-tests for the cancer group revealed an increase in depression scores from time 1 to time 2 $t(37) = -2.21$ $p<0.034$ and a significant decrease in symptoms from time 2 to time 3 $t(37) = 2.45$ $p<0.019$, but no significant differences were found for the control group. Independent sample t-tests revealed that the cancer group had significantly higher scores than the control group on the depression subscale of the SCL-90 at time 2 $t(95) = 3.97$ $p<0.000$. Mean scores are depicted in Figure 5.

The repeated measure ANOVA for the SCL-90 anxiety scale showed a significant effect of group membership $F(1, 95) = 6.34$ $p<0.01$ and marginally significant interaction of groups X time $F(3, 93) = 2.32$ $p<0.08$. There was no significant effect for the within-group effect of time. Paired sample t-tests revealed that for both the cancer and the control group there was no significant change through time on the anxiety subscale of the SCL-90. Independent sample t-tests revealed that the cancer group had significantly higher scores than the control group on the anxiety subscale of the SCL-90 at time 1 $t(95) = 2.92$ $p<0.004$ and at time 2 $t(95) = 3.392$ $p<0.001$. Mean score are depicted in Figure 6.

Perceived Stress Scale

The repeated measure ANOVA for the PSS scale score produced a different pattern of results. In contrast to the PTSD scales, there was no significant effect of group

membership on its own. The interaction of groups X time was significant F (2,115) =3.47 $p<0.03$. The within-group effect of time was significant F (2, 115) =9.58 $p<0.000$. Paired sample t-tests for the cancer group revealed a significant decrease in PSS scores from time 1 to time 3[8] t (54)= 2.588 $p<0.012$ and a significant decrease for the control group from time 1 to time 3 t (62) = 2.44 $p<0.018$. Independent sample t-tests revealed that the cancer group had higher scores than the control group on the PSS at time 1 t (116) = 2.10 $p<0.038$. Mean scores are depicted in Figure 7.

Functional Assessment of Cancer Therapy-General

The repeated measure ANOVA for the FACT-quality of life, the between-group effect was not significant. The within-group effect of time was significant F (2, 115) =3.27 $p<0.04$. The interaction of group X time was significant F (2, 115) = 5.24 $p<0.007$. Paired sample t-tests revealed that for both the cancer and the control group there was no significant change through time on the FACT quality of life scale. Independent sample t-tests revealed that the control group had significantly higher scores than the cancer group on the FACT quality of life scale at time 1 t (116) = -2.47 $p<0.015$. Mean scores are depicted in Figure 8.

Social Readjustment Rating Scale

In terms of life stress as measured by the SRRS, an ANOVA was performed (only a single time point was available) there was a statistically significant difference between the cancer and control groups. Cancer patients reported higher stress at time 4: 184.78 (SD=121.93) compared to controls 135.74 (SD=84.19), F (1, 101) = 5.836 $p<0.017$.

Correlations between independent variables and PTSD

[8] The PSS was not administered at time 2.

Table 4 presents the correlation between independent variables and PTSD. For sociodemographic variables for cancer patients, point-biserial correlations were performed. Marital status was inversely correlated, $r = -.22$, $p<0.05$ with anxiety at time 1, income was negatively correlated to anxiety at time 1, $r = -.27$, $p<0.05$ and at time 3 ($r=-.32$). Parental status was negatively correlated to anxiety at time 1 $r = -.23$, $p<0.05$ and age was negatively correlated to depression at time 4, $r = -.28$, $p<0.05$. Level of education and employment were never correlated to any of the outcome measures. None of the sociodemographic variables related to any of the outcome variables for the control group. Contrary to what was predicted, none of the demographic variables correlated with PTSD measures.

Consistent with initial predictions, correlations between key variables showed strong positive associations between both depression and anxiety with both of the PTSD scales (IES and PCL-C) for both the cancer patients and the controls at all time points. The PSS was also strongly and positively related to depression, anxiety, IES and PCL-C scores, for both groups at all time points. As expected, the FACT quality of life scale was negatively correlated with depression, anxiety, IES and PCL-C scores for both groups at all time points. The SRSS at time 4 was related to depression, anxiety, IES and PCL-C at time 1, to depression and PCL-C at time 2, unrelated to all measures at time 3 and related to depression at time 4 for the cancer groups only. Except for a correlation with the PCL-C at time 1, the SRSS at time 4 was unrelated to all measures at all time points for the controls (see table 4). Contrary to prediction, history of trauma was not correlated with the IES, the PCL-C, or the SCL-90 depression and anxiety scales for the controls. For the cancer patients, the only significant correlation for history of trauma was with depression at time 1 ($r=.223$, $p<0.05$).

Regressions

In order to test the fourth hypothesis that age, history of trauma, education and income would increase the likelihood of PTSD symptoms, these variables were introduced in a linear regression to predict PTSD at time 4. While correlations already indicated non-existent to low relations between these variables sociodemographic variables and PTSD, the regression model repeated the non-significant findings, thus disconfirming the fourth hypothesis.

Next, stepwise regressions were performed to determine what factors had an overall influence on levels of PTSD 1 year post-diagnosis. Two sets of regressions were performed, with either the IES or the PCL-C total scores used as the dependent measures. In order to predict PTSD symptoms at time 4 the following time 1 variables were entered in a linear regression: PTSD (either on the IES or the PCL-C) was controlled first, and then depression, anxiety, quality of life and perceived stress were entered in the model. For the cancer group, the model using the IES time 4 as the dependent variable revealed depression as a significant predictor of IES at time 4 once IES at time 1 was controlled, $\beta = .31$, $t(53) = 3.0$, $p < .01$. The model generated a reasonable fit (Adjusted $R^2 = 0.55$) and the overall relationship was statistically significant ($F(2, 53) = 35.253$, $p < 0.000$). Apart for a significant effect of depression at time 1 on IES levels at time 4 for the cancer group, depression, anxiety, quality of life and perceived stress were all non-significant once the initial levels of PTSD (either on the IES or PCL-C) was controlled. For the control group, only the IES at time 1 was a significant predictor of the IES at time 4. It accounted for 31.4% of the variance ($F(1, 64) = 30.776$, $p < 0.000$). In the model using the PCL-C at time 4 as the dependent variable, only the PCL-C at time 1 was significant predictors for the cancer groups (Adjusted R2= 54.5%). For the control group, only the

PCL-C at time 1 was a significant predictor of the PCL-C at time 4 (Adjusted R2= 30.3%).

A set of logistic regressions were performed to explore whether previous exposure to trauma had an impact on PTSD scores at time 4. The presence of previous exposure to trauma was coded as present or absent, this represents the independent variable. The presence of PTSD at time 4 on the IES and the PCL-C was dichotomized as present (moderate to severe symptoms) or absent (none or low levels of symptoms), this was the dependent variable. Two sets of logistic regressions were performed, one for the cancer patients, and one for the control group. For the cancer patients, those who were exposed to a prior traumatic event, marginally significant results point to the possibility that they were about 3 time more likely to have current PTSD on the IES at time 4 than those who were not exposed Exp(B)=3.426 (1, 56) $p<0.08$. The effect of previous exposure to a traumatic event did not have a significant effect on current PTSD scores for the control groups on the IES. The effect of previous exposure to trauma on the PCL-C was not significant for neither of the groups.

In summary, variables which share a relation with PTSD, such as perceived stress, quality of life, and anxiety, do not predict PTSD when early levels of PTSD are controlled. For controls, only previous measurements of PTSD were significant predictors of PTSD at time 4. The bulk of the variance in predicting the PTSD scores at time 4 is taken up by original PTSD scores at time 1, which is consistent with our second hypothesis (once PTSD symptoms arise they tend to persist over time). Analyses of covariance (ANCOVA) revealed that once levels of PTSD on the IES and PCL-C at time 1 were controlled; there was still a significant difference between the cancer and the control group at time 4 on these same measures of PTSD. Groups were significantly

different on the IES at time 4 when IES at time 1 was controlled $F=4.311$ (1, 125) $p<0.04$ and on the PCL-C time 4 when the PCL-C time 1 was controlled $F=4.602$ (1, 120) $p<0.03$[9].

Discussion

The objectives of this study were to determine the frequency of cancer-related of PTSD symptoms in young male cancer patients, to understand how symptoms of cancer-related PTSD evolved in the first year following cancer diagnosis and to identify risk factors that were predictive of PTSD symptoms. Findings of this study parallel previous reports of PTSD in cancer patients (Cordova et al., 1995) and provide further support for the applicability of the PTSD construct to the cancer diagnoses. As was predicted, the cancer patients had significantly greater PTSD symptom severity than the controls at every time point on both the PCL-C except at time 1 and had higher levels of PTSD than controls at time 2 and 4 on the IES. At time 1 there was no difference between the cancer and control groups on both measures of PTSD. At time 1, the patients had not yet started their chemotherapy or radiotherapy treatments and this perhaps explains why they had no PTSD-like symptoms regarding the cancer experience. However, they had a higher anxiety level than the controls, also perhaps related to the fact that treatments were not yet started and patients had much uncertainty about what to expect in terms of medical procedures. This may also be due to a sensitization to the measure for controls, making them evaluate past stressors as salient, or may also be due to the fact that about one quarter of the controls were dealing with a recent diagnosis of infertility.

[9] Results for the log-transformed data on the IES and PCL-C produced outcomes that were comparable in significance and effect size.

Overall, there was a lower incidence of PTSD in this study than that which is found in war exposure (18 to 54%) (Oei, Lim, & Hennessy, 1990) or in rape victims (16 to 60%) (Resnick, Kilpatrick, Dansky, Saunders, & Best, 1993). However, PTSD symptom severity was either comparable or slightly lower than that of other cancer populations. Mean scores on the PCL-C for cancer patients in this study ranged from 26.66 to 29.87 for the final sample and from 26.96 to 31.25 for the cross-sectional data. These results are very similar to results reported in a cross-sectional study of breast cancer survivors who had a mean of 27.1 (SD=12.7) on the PCL-C (Cordova et al., 1995). In our study, the percentage of cancer patients who could be considered as fitting the DSM-IV criteria for PTSD (PCL-C score of 50 and above) ranged from 3.4% to 8.3% (cross-sectional sample) from time 1 to 4. In a sample of 82 breast cancer survivors (mean age: 56.6; mean of 37 months post-treatment), there was a 5% prevalence of current PTSD related to cancer on the PCL-C (cut-off score of 50 and above) (Andrykowski et al., 1998). However, subsyndromal (cut-off of 40 and above) frequency of PTSD had a range 13.6 to 22.2% in our study (cross-sectional scores), which is at least two-fold that of controls at time 2 to 4.

Mean scores on the IES for cancer patients ranged from 14.78 to 17.97 for the final sample and 16.24 to 20.98 for the cross-sectional data. Two distinct studies of breast cancer survivors reported means of 16.4 (SD=18) (Cordova et al., 1995) and 31 (SD=14.6) (Butler et al., 1999). In this study, there was between 7% and 14.3% of cancer patients who had severe symptoms, and between 21.2% and 34.9% who had moderate to severe symptoms on the IES (cross-sectional scores cut-off of above 26). This is substantially lower than reports from breast cancer survivors. Butler et al. (1999) using a cut-off score of 30 reported that 52% of the survivors scored in the severe range category.

Our findings are significantly lower than one study of breast cancer survivors (Butler et al., 1999), which is consistent with the literature suggesting higher incidence in females that males (Kangas et al., 2005a, 2005b; Olff et al., 2007). These differences could be due to the worse prognosis associated with breast cancer, but are perhaps illustrative of gender differences in the frequency of PTSD symptoms.

In terms of the evolution of PTSD symptoms over the first year since diagnosis, there was a significant effect for the group X time interaction; only the control participants experienced a decrease in symptoms over time. The cancer patients had a higher and increasing level of PTSD symptoms over time. This finding is inconsistent with previous longitudinal studies that reported the highest level of cancer-related PTSD at the time of diagnosis followed by a gradual decline over time (Kangas et al., 2005a, 2005b, 2005c, 2005d; Manuel et al., 1987). Also, the current study pointed to the pervasiveness of early PTSD symptoms.

Depression scores increased for the cancer patients from time 1 to time 2 but then decreased significantly from time 2 to time 3. Anxiety scores did not fluctuate over time for neither the cancer group nor the control group. Depression and anxiety scores also tended to be higher for cancer patients than the controls. Contrastingly, there was no group difference for perceived stress and for quality of life.

These results point to the distinctive nature of PTSD responses in cancer patients when compared to adjustment in terms of general stress or quality of life. Cancer patients expressed the same level of general stress and health-related quality of life as a sample composed mostly of college students and infertile males; however their symptoms of PTSD were in every case more elevated. Our results suggest that cancer patients are not overall worse off than healthy controls, and that this is not an undifferentiated effect on

every measure of psychosocial adaptation. While they are experiencing higher levels of depression and anxiety than controls, these symptoms decrease over time, but PTSD does not. This brings about questions concerning measurement and meaning of PTSD symptoms in cancer patients.

Measurement of PTSD is limited by the instruments that were employed. While the IES asks about the frequency of intrusive thoughts and avoidance, the IES does not assess whether these experiences are actually distressing for the patient. Whether these symptoms result in impairment, problematic ruminations and distress is unclear. However, the use of the PCL-C as a second instrument to assess PTSD symptoms did take distress into account. In this study, incidence rates of cases of moderate to severe PTSD symptoms were consistently lower on the PCL-C than on the IES. It could possibly be that a certain proportion of individuals score high on the IES but not on the PCL-C as they may be experiencing some cognitive symptoms but are not distressed about them.

One possible way of understanding the data is by introducing the concepts of cognitive integration and processing. Certainly, thinking about an experience is not problematic in itself; it may even be beneficial in terms of cognitive integration. Perhaps the high correlations and predictive value of depression on PTSD can indicate that these symptoms are in fact distressing for a number of patients for some time, but perhaps not all. As anxiety and depression wane over time and PTSD symptoms increase, it may be the case that PTSD symptoms are not as distressful as expected in a clinical sense, but may represent a form of cognitive processing. As seen in our study, cancer patients did not differ from control participants in terms of quality of life or perceived stress. Avoidance may be adaptive in the face of immediate trauma, but may become counter-productive if it goes on for too long (Brennan, 2001; Foa, Stekee, Rothbaum, 1989;

McMillen, North, Smith, 2000; Suls & Fletcher, 1985). Efforts not to think about the event prevent individuals from elaborating the trauma memory and linking their experience with its context in time, space, previous and subsequent information and other autobiographical memories. Such efforts also prevent changes in appraisals. Reconstruction emphasizes on what is unchanged by the experience, incorporation recognizes the opportunity offered by the experience to develop and expand a pre-existent facet of identity (Little, Paul, Jordens, Sayers, 2002). It is possible that the search for meaning, through cognitive processing of the experience, allows acceptance and incorporation (Little et al., 2002). Reminiscence of the traumatic event may lead to positive reappraisals or may lead to the integration of the new experience in the existing set of beliefs of the individual (Brennan, 2001). In the current study, there was a significant increase in intrusion score from time 3 to time 4, but there were no significant changes in avoidance scores over time for the cancer group. Positive appraisals and reappraisals of a traumatic event have been linked to faster cortisol habituation to subsequent stressors, indicating a greater flexibility in the system. Positive reappraisal of the trauma may therefore serve as a protection against developing PTSD (Epel, McEwen, & Ickovics, 1998).

Contrary to expectation, demographic variables did not predict any significant variance in PTSD symptoms. Except for a correlation with the PCL-C at time 1, the SRSS was unrelated to all measures at all time points for the controls. Also contrary to prediction, history of trauma was uncorrelated to the IES, the PCL-C, depression and anxiety scales for the controls, and only correlated to depression at time 1 for the cancer patients. However, in the logistic regressions exposure to a prior traumatic event

increased the likelihood to have current PTSD on the IES for cancer patients but not for controls.

There is certainly an important relation between depression and PTSD for cancer patients on the IES, which remains significant when early levels of PTSD are controlled as in this study. Variables which share a relation with PTSD, such as perceived stress, quality of life, and anxiety, do not predict PTSD when early levels of PTSD are controlled, or when depression levels are controlled. The nature of this association has been brought into question in light of studies reporting correlations between depression and PTSD as high as $r=0.70$ $p<0.001$ (Epping-Jordan et al., 1999; Neria & Bromet, 2000). The overlap in measurement of depression, anxiety and PTSD produces quantitatively high collinearity. Because concepts such as intrusions resemble anxious thoughts about the future, and depressed mood may resemble numbing, qualitative work is needed to clarify this relation.

One of the limitations of the study is the voluntary and non-random recruitment of the participants. The conclusions of this study are limited by our sample size. Failure to demonstrate a difference between groups or between time points may be due to lack of statistical power. Moreover, patients dropping out of the study limited the power of longitudinal analyses by reducing the sample size even further. Data replacement cannot be performed to replace entire time points for those who missed an assessment. When reporting longitudinal analyses, only complete cases can be used, or it is impossible to make an argument for the effect of time. Missing data was problematic as analyses need to be done on the same individuals through time. Also there was a low variability in age, marital status and education; the sample may not be representative of the population. Furthermore, the healthy control sample was heterogeneous with regard to being

composed of infertile men and men from the general community. The community controls self-identified a stressful event in their past. The time elapsed since the given event was on average three to four time the amount of time elapsed at each time point since the cancer diagnosis of the patient group[10], which means that their PTSD scores might have been lowered by the effect of time. Ideally, cancer patients would be compared to a group of men recently diagnosed with a homogenous non-life threatening condition to compare the outcomes in both groups. Another limitation concerns the measurement of stressful life events on the SRRS which were only measured at time 4. Future research could attempt to measure stressful life events in the year preceding the first assessment. This would allow controlling baseline differences between groups on the basis of recent life stress. Future research could also attempt to measure personality characteristics associated with PTSD which would allow speaking about individual differences in the development of PTSD. As frequency of PTSD-like cases in our sample were similar or a bit lower than what was presented in other studies, and given the great variability in reported prevalence in the literature (Kangas et al., 2002) meta-analyses would be needed to make further conclusions. Finally, a deeper study of the expression of cancer-related PTSD symptoms, in the form of clinical interviews, case studies or qualitative studies, would clarify the amount of distress that is associated with these symptoms. The IES while being a very frequently used instrument to assess symptoms of intrusions and avoidance does not assess whether these symptoms are accompanied by an impaired functioning and distress following the stressful event. Future studies would

[10] At time 1, the mean number of months elapsed since diagnosis for cancer patients was 1.88 months, 5.44 months at time 2, 8.68 months at time 3 and 14 months at time 4. For control participants, the mean number of months elapsed since their reported stressful events was 26.16 months at time 1, 37.03 months at time 2, 37.96 months at time 3 and 40.99 months at time 4.

benefit from using diagnostic tools such as semi-structured clinical interviews and more research is needed to determine whether symptoms of PTSD are maladaptive (i.e.: prolonged avoidance). Self-efficacy and appraisal of symptoms (not of the event itself) may be good indicators of who may develop higher distress.

Conclusion

Cancer-related PTSD can be observed in a minority of cancer survivors, which indicates a fairly good adjustment for most cancer patients. The cancer experience is a stressor on a chronic basis, disruptions of normal functioning are present from diagnosis and may persist over the long-term remission phase. As a return to health gradually takes place, depression and anxiety symptoms wane, but PTSD symptoms remain stable. Whether these symptoms are associated with decreased functioning or are an expression of cognitive integration of the experience is yet to be investigated. Health care workers can gain by understanding factors and moments in which patients are more psychologically fragile. This would allow them adapt their practice so that care will be provided more efficiently to those who are most in need of it.

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Tables

Table 1
Sociodemographic characteristics of sample

	Cancer patients	n	Combined controls	n
Age				
Mean	27.3	92	26.9	88
Standard deviation	6.71		6.66	
Median	26		26	
Range	16-50		18-46	
First language%				
French	33.7	31	34.1	30
English	50	46	29.5	26
Other	16.4	15	36.4	32
Marital status%				
Single	62	57	67.1	59
Married	19.6	18	20.5	18
Divorced/Separated	3.3	3	6.8	6
Common law	15.2	14	4.5	4
Refusal/no answer	0	0	1.1	1
Parental status %				
Children	10.9	14	6.8	6
No Children	83.7	77	93.2	82
Refusal/no answer	1.1	1	0	0
Education%				
Some high school	14.1	13	4.5	4
Completed High School	17.4	16	6.8	6
Some College	21.8	20	5.7	5
Some or completed University	46.8	43	83	73
Employment %				
Full-time	55.4	51	33	29
Part-time	5.4	5	13.6	12
Temporarily not working	12	11	4.5	4
Unemployed	7.6	7	2.3	2
Student	17.4	16	44.3	39
At home	1.1	1	1.15	1
Refusal/no answer	1.1	1	1.15	1
Income%				
Less than $20 000	14.1	13	28.4	25
20 to $39 000	17.4	16	19.3	17
40 to $59 000	25	23	12.5	11
60 to $79 000	6.5	6	2.3	2
80 to $100 000	8.7	8	5.7	5
More than $100 000	13	12	15.9	14
Refusal/no answer	15.2	14	15.9	14

Table 2
Previous exposure to a traumatic event

	Previous trauma	No previous trauma	Total n
Cancer patients	18.5% (n=17)	81.5% (n=75)	(n=92)
Combined Controls	26.2% (n=23)	73.8% (n=65)	(n=88)
Total	(n=40)	(n=140)	(n=180)

Table 3
PTSD symptoms severity frequencies per group

	Time 1		Time 2		Time 3		Time 4	
	Cancer patients	Combined controls	Cancer patients	Combined controls	Cancer patients	Combined controls	Cancer patient	Combined controls
IES								
N	92	88	63	76	71	67	57	66
None	26.1%	47.7%	31.8%	65.8%	32.4%	61.2%	42.1%	62.1%
Mild	39.1%	31.8%	33.3%	18.4%	46.5%	20.9%	33.3%	22.7%
Moderate	26.1%	14.8%	20.6%	14.5%	12.7%	16.4%	17.5%	13.6%
Severe	8.7%	5.7%	14.3%	1.3%	8.5%	1.5%	7%	1.5%
PCL-C								
N	88	88	63	76	72	67	58	66
None	86.4%	87.5%	78%	96.1%	83.3%	92.5%	79.3%	90.9%
Moderate	10.2%	9.1%	15.9%	0%	8.3%	6%	17.2%	6.1%
Severe	3.4%	3.4%	6.3%	3.9%	8.3%	1.5%	3.5%	3%

LEGEND: IES scoring: 0-8 none; 9-25 mild; 26-43 moderate; 44 and+ severe (range 0 to 75) PCL-C scoring: 0-39 none; 40-49 sub-clinical (moderate); 50 and + severe (range 17 to 85)

Table 4

Summary of intercorrelations between scales for the cancer and control group

Variables	Cancer group				Combined controls			
	DEP	ANX	IES	PCL	DEP	ANX	IES	PCL
	Time1	Time1	Time1	Time1	Time1	Time1	Time1	Time1
IES t1	.50**	.60**	1	.64**	.46**	.31**	1	.71**
PSS t1	.53**	.52**	.43**	.50**	.62**	.56**	.29**	.46**
PCL-Ct1	.70**	.70**	.64**	1	.55**	.47**	.71**	1
Fact QOL t1	-.62**	-.45**	-.37**	-.47**	-.67**	-.48**	-31**	-.43**
SRSSt4	.42**	.46**	.38*	.51*	.19	.22	.11	.29*
Marital status	-.09	-.22*	-.01	-.14	-.05	-.09	-.11	-.07
Income	-.12	-.26	-.07	-.07	.01	.02	.01	-.15
Parental status	-.17	-.23*	-.12	-.14	.03	-.08	.06	.01
	Time2	Time2	Time2	Time2	Time2	Time2	Time2	Time2
IES t2	.62**	.66**	1	.85**	.42**	.30**	1	.60**
PCL-Ct2	.75**	.73**	.85**	1	.51*	.57**	.60**	1
SRSSt4	.40*	.31	.24	.34*	.16	.12	.14	.04
	Time3	Time3	Time3	Time3	Time3	Time3	Time3	Time3
IES t3	.63**	.68**	1	.78**	.57**	.49**	1	.78**
PSS t3	.79**	.69**	.50**	.70**	.65**	.58**	.46**	.50**
PCL-Ct3	.76**	.78**	.78**	1	.65**	.65**	.78**	1
Fact QOL t3	-.84**	-.70**	-.61**	-.77**	-.70**	-.55**	-31*	-.40**
SRSSt4	-.01	-.01	.13	.16	.28*	.23	.08	.08
Income	-.23	-.32	-.17	-.25	-.18	-.08	-.11	-.02
	Time4	Time4	Time4	Time4	Time4	Time4	Time4	Time4
IES t4	.62**	.65**	1	.85**	.44**	.52**	1	.81**
PSS t4	.82**	.71**	.49**	.68**	.55**	.56**	.27*	.31*
PCL-Ct4	.75**	.78**	.85**	1	.58**	.65**	.81**	1
Fact QOL t1	-.85**	-.73**	-.62**	-.79**	-.58**	-.60**	-.35**	-.47**
SRSSt4	.53**	.41**	.26	.30	.11	.14	-.02	.15
Age	-.28*	-.23	.04	-.04	-.05	.10	.13	.13

LEGEND: DEP= SCL-90 depression score; ANX: SCL-90 anxiety scores; IES: impact of event scale total score; PCL-C: posttraumatic checklist-civilian total score; SRSS= Social Readjustment Stress Scale; Fact-QOL: Quality of life

Figures

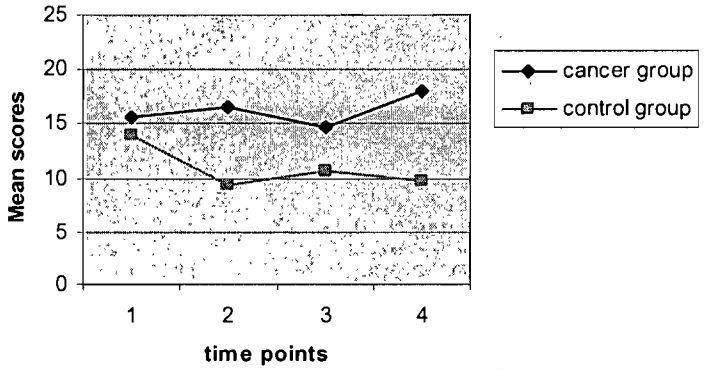

Figure 1. IES scores for the final sample per group through time

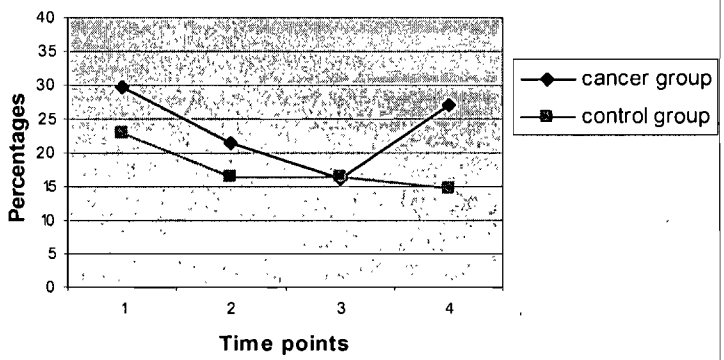

Figure 2. Percentage of elevated PTSD symptoms on the IES for the final sample per group through time

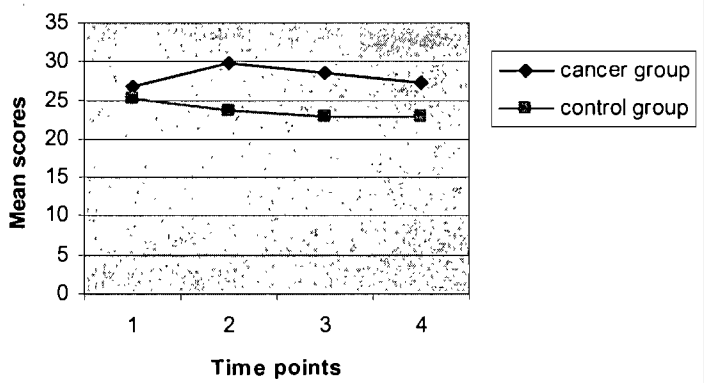

Figure 3. PCL-C scores for the final sample per group through time

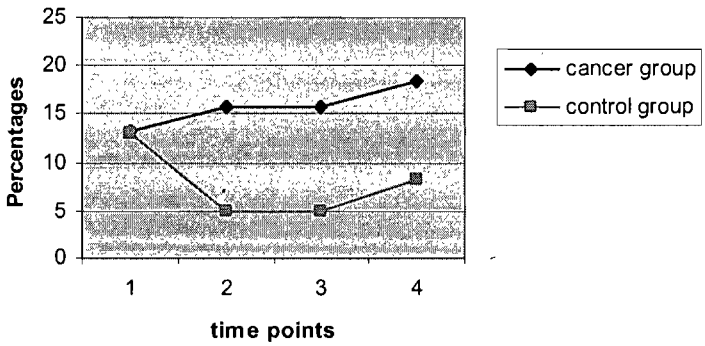

Figure 4. Percentage of elevated PTSD symptoms on the PCL-C for the final sample per group through time

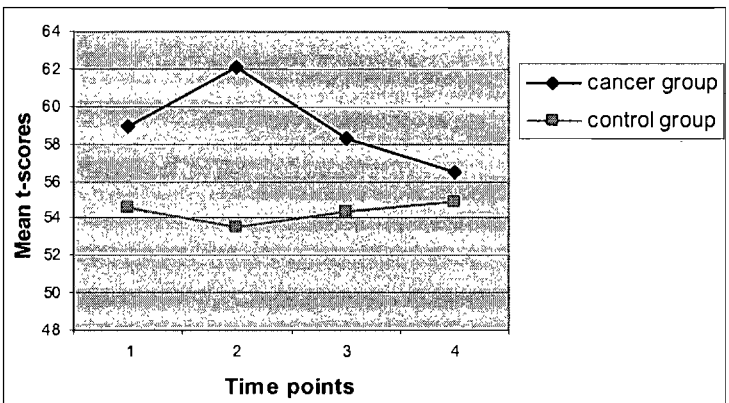

Figure 5. Depression scores for the final sample per group through time

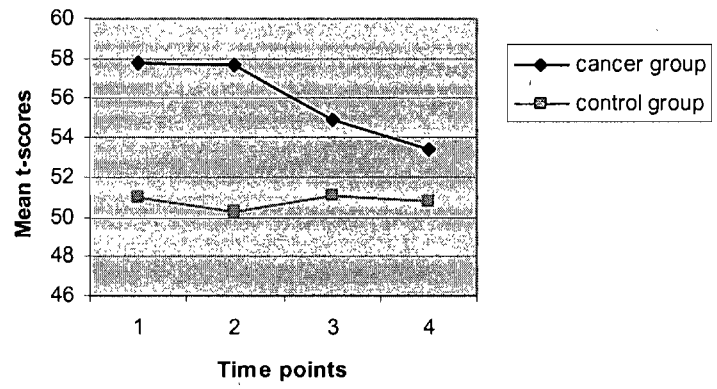

Figure 6. Anxiety scores for the final sample per group through time

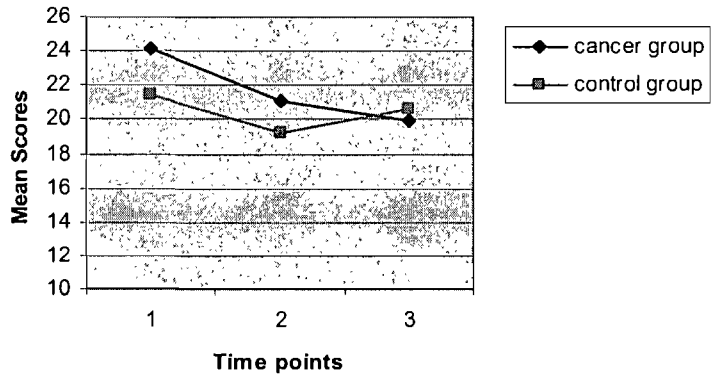

Figure 7. PSS scores for the final sample per group through time

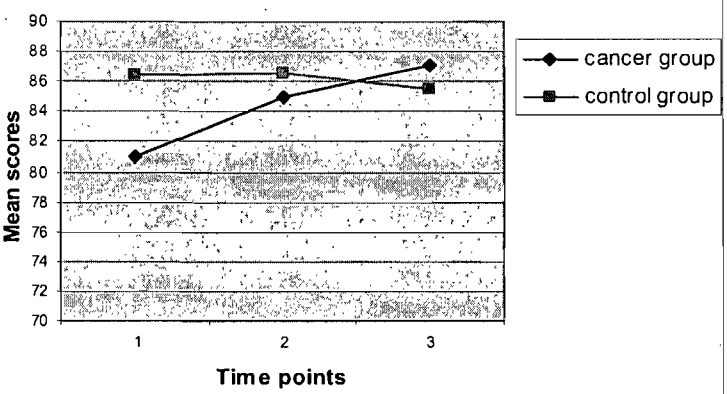

Figure 8. FACT-G: (quality of life) scores for the final sample per group through time

APPENDIX 1: Events reported as history of exposure to traumatic events

Coded as traumatic:	**Frequency**
Car accident	13
Witnessing an explosion in Israel	1
Plane ride through a storm with lots of turbulence	1
Armed thief stole car	1
Mugged at knife point	6
Hit be a car while on roller blades/bike/ walking	4
House being robbed while still inside the house	1
Being kidnapped along with friends	1
Heart attack or stroke	2
Suspended in the air of an elevator shaft on the 11^{th} floor	1
Caught in a rock slide on a mountain	1
Bank robbery witness	1
Armed robbery/being held at gun point in a store	2
Attacked by a man with a metal bar and being hit across the head	1
Severe chocking on food, couldn't breathe	1
Past cancer diagnosis	1
Being a UN representative in Iraq in 1995-1996 and being caught in a cross-fire	1
Was in Kuwait when invasion started	1

Coded as non-traumatic:	**Frequency**
Father died from natural causes:	2
Separated from wife, romantic partner	2
Could have drowned	1
Benign tumour	1
Injury during a hockey game	1
Attempted suicide in 1996 and 2000	1
Epileptic episode	1
Almost had a motorbike accident	1
Witnessed a car accident of strangers	1
Mother in law broke her back	1
Girlfriend's mother was diagnosed with cancer	1
Diagnosed with diabetes	1
Ice climbing	1
Being in a physical fight	1

APPENDIX 2: Characteristics of drop-outs vs. completed sample

Table 5
Characteristics of drop-outs vs. completed sample

	Cancer group						Control group				
		Mean	STD	t	df	Sig p<	Mean	STD	t	df	Sig p<
Age	Drop-out	26.7	7.1	-.87	89	.38	28.2	7.54	1.25	86	.22
	Complete	27.97	6.2				26.3	6.20			
	Complete	1.7	.48				1.4	.5			
Intrusions t1	Drop-out	10.7	8.2	2.19	90	.03	5.9	7.7	-.44	86	.66
	Complete	7.1	6.5				6.8	8.8			
Avoidance t1	Drop-out	11.5	7.9	1.69	90	.09	6.3	8.2	-.52	86	.61
	Complete	8.5	8.7				7.3	8.3			
IES t1	Drop-out	22.2	14.7	2.18	90	.03	12.2	15.4	-.51	86	.61
	Complete	15.7	13.0				14.1	15.6			
PSS t1	Drop-out	25.3	6.3	1.29	89	.20	22.1	7.7	.50	86	.62
	Complete	23.3	8.1				21.3	6.9			
PCL-C t1	Drop-out	28.98	9.0	1.22	86	.23	25.2	14.3	.01	86	.997
	Complete	26.7	8.6				25.2	9.5			
Depression t1	Drop-out	62.9	10.1	1.77	90	.08	53.4	11.6	-.51	86	.61
	Complete	58.7	12.4				54.7	11.2			
Anxiety t1	Drop-out	60.8	11.1	1.26	90	.21	49.2	10.8	-.78	86	.44
	Complete	57.7	12.2				51.1	10.6			
Fact qol t1	Drop-out	77.98	14.4	-1.49	90	.14	87.8	11.0	.68	86	.50
	Complete	82.5	13.7				86.1	10.7			

Table 6
Retention per time point and drop-out motives

		cancer	Control
Time 1	completed	92	88
Time2	completed	63	76
Time 3	completed	71	67
Time 4	completed	57	66
All time points	completed	38	61
Drop-outs	Did not receive time 2	19	
	deceased	4	
	Ineligible	2	
	Drop-out	6	24
	Not yet reached a time point	23	3

Attrition details

At time 2, there were 63 cancer patients who completed the study, there were 17 cancer patients did not receive time 2 (time 2 started some months after the beginning of initial recruitment, hence some of the first participants did not receive time 2), 2 were unreachable by phone after 3 attempts, 3 deceased, 2 dropped out (didn't want to pursue), 2 were ineligible (1 wasn't going to receive chemo, 1 was too ill to pursue the study), and 3 had no data available for that time point because they had not reached that measurement point yet (recently entered the study). There were 76 controls that filled time 2. Of those missing, one did not receive time 2 (but complete further time points), 3 were unreachable by phone at time 2, 5 dropped out, 3 had no data available yet for that time point. Of those who were unreachable, 2 filled out time 3 and 4, and one filled out only time 4.

At time 3, there were 71 cancer patients who completed the study. Out of the total initial sample (92): 1 missed his scheduled appointment for the study at time 3 (but filled time 4), 5 dropped-out, 4 deceased, 11 had no data yet available for that time point. There were 67 controls that filled time 3, 1 remained unreachable (but filled time 4) 16 participants dropped out (mostly infertile controls, one moved away to another continent), 1 missed his scheduled appointment (but filled time 4), and 3 had not yet reached that time point. At time 4, 57 cancer patients completed the questionnaires. Of the total initial sample (92), 2 were ineligible, 6 participants who dropped out of the study, 4 deceased and 23 had not reached that time point yet.

When considering the total number of individuals that were available from the initial sample to complete time 4 (not counting those who had not yet reached that measurement

point, those who passed away, or ineligible), the retention rate in the study for cancer patients was 87.7%. There were 66 controls that filled time 4. From the total initial sample (88), 19 dropped-out and 3 had not yet reached that time point. When considering the total number of individuals that were available from the initial sample to complete time 4 (not counting those who had not yet reached that measurement) the retention rate in the study for controls was 77.6%. As such, at time 4 there were 38 cancer patients (38/46 response rate of available candidates who filled all time points is 82.6%- considering that 17 were not even exposed to time 2, 23 had not reached the end of the study, 2 were ineligible and 4 deceased)- and 61 controls (response rate of available candidates who filled all time points is – 72.6% considering that 1 had not been exposed to time 2 and 3 had not yet reached the end of the study) who had filled out all four time points (hereafter called the final sample).

APPENDIX 3: Events reported by controls on the IES and PCL-C at time 1

Coded as traumatic:	**Frequency**
Car accident	5
Head injury bike accident	1
House robbery	1
Kidnapped/mugged	1
Heart attack	1
Robbed at knife point	1
Caught in a gun fire	1
Suspended in the air in an elevator shaft for hours on the 11th floor	1
Bank robbery	1
Armed robbery	1

Coded as non traumatic:	**Frequency**
Schoolwork, exams	7
Dog died	1
Failed exam, failed a class	2
Death of hamster	1
Relationship breakup/separation/divorce	9
Benign tumor	1
Meeting with supervisor	1
Girlfriend is away	1
Fired from job	1
Death of a relative	4
Psychotic episode	1
Parents' ill health	3
Announcing homosexuality	1
Anxiety attack	1
Attempted suicide	1
Epileptic seizure	1
Blushing in public	1
First witness to a car accident	1
Student strike	1
Trip to Nicaragua	1
Disqualified from an international regatta	1
Threat of fine for violation of copyright	1
Applying to grad school, school choices	2
Lost passport	1
Plane ride	1
New job, job search	2
Verbal fight	1
Moving to Montreal	1

Additional events reported at other time points[1]

Coded as traumatic:	**Frequency**
Attacked by a gang of 6 men	1
Motorized vehicle accident	4
Mugged at knife point	1
Fell down a dam	1
House robbery	1
Being physically assaulted	1

Coded as non traumatic:	**Frequency**
Major misunderstanding	2
Putting out a large camp fire	1
Broke a leg, psychical injury	2
Starting university	1
Travelling alone in Europe	1
Hit by drunk mother	1
Heard the news about a friend being raped	1
Job search	1
Relationship break up	2
School work, Exam period	5
Graduation	1
Feeling depressed	1
Problem accessing government loans	1

[1] These events represent a change from previously reported events either from none reported or from another event previously reported.

APPENDIX 4: Figures for the cross-sectional data

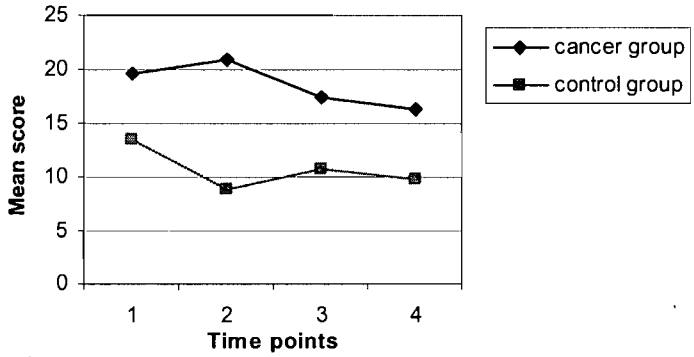

Figure1-A. IES scores for the cross-sectional sample per group through time

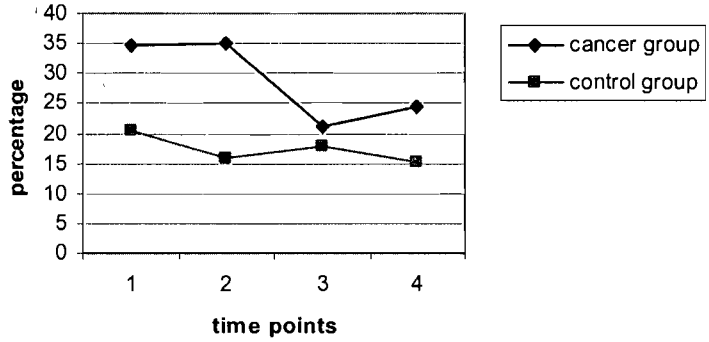

Figure 2-A. Percentage of elevated PTSD symptoms on the IESfor the cross-sectional sample per group through time

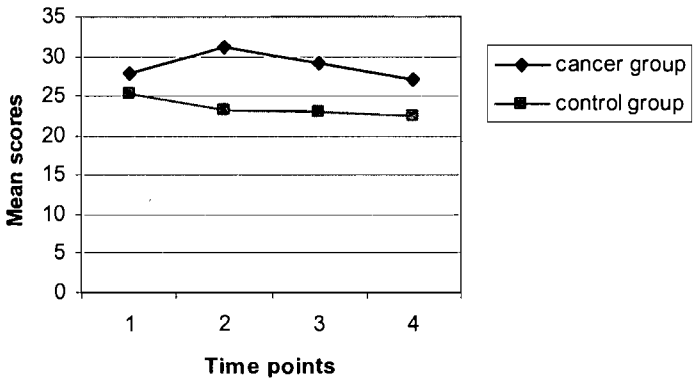

Figure 3-A. PCL-C scores for the cross-sectional sample per group through time

APPENDIX 4: Figures for the cross-sectional data

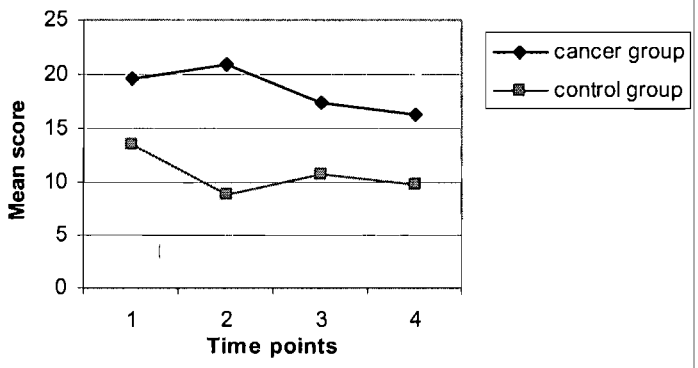

Figure1-A. IES scores for the cross-sectional sample per group through time

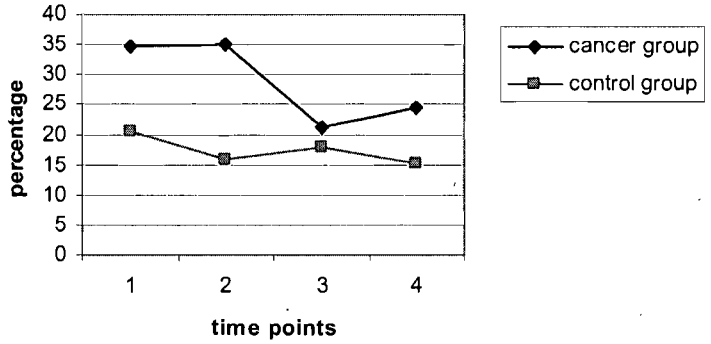

Figure 2-A. Percentage of elevated PTSD symptoms on the IESfor the cross-sectional sample per group through time

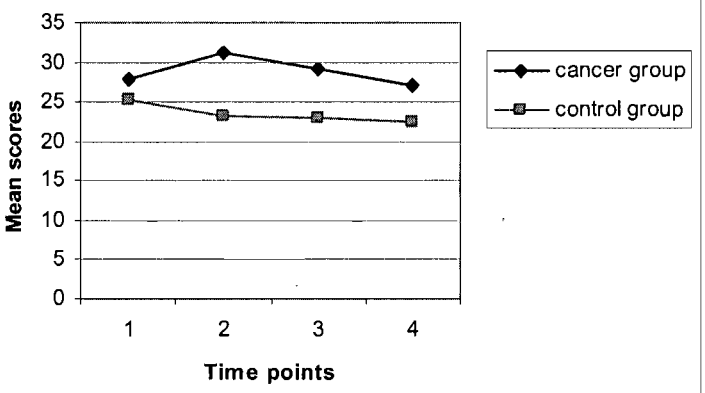

Figure 3-A. PCL-C scores for the cross-sectional sample per group through time

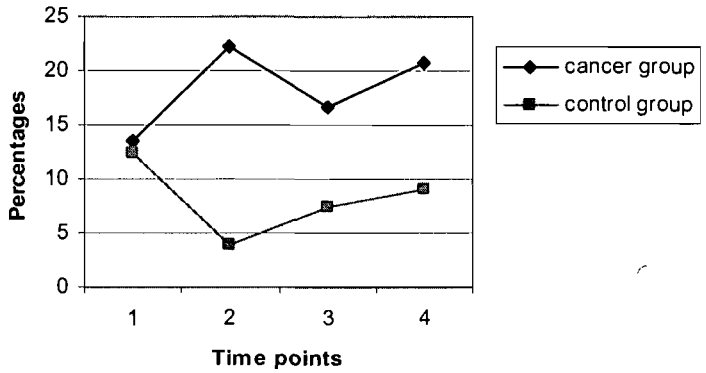

Figure 4-A. Percentage of elevated PTSD symtpoms on the PCL-C for the cross-sectional sample per group through time

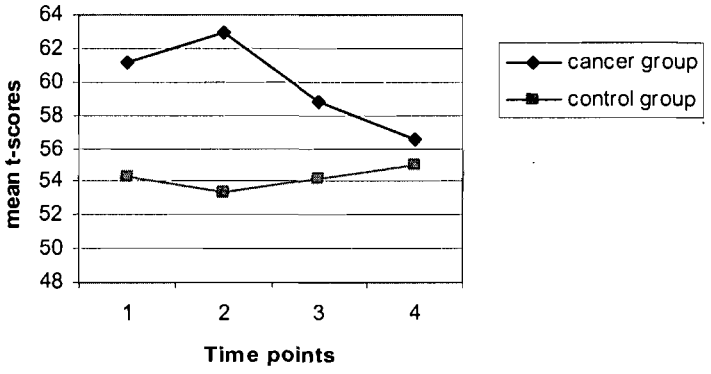

Figure 5-A. Depression scores for the cross-sectional sample per group through time

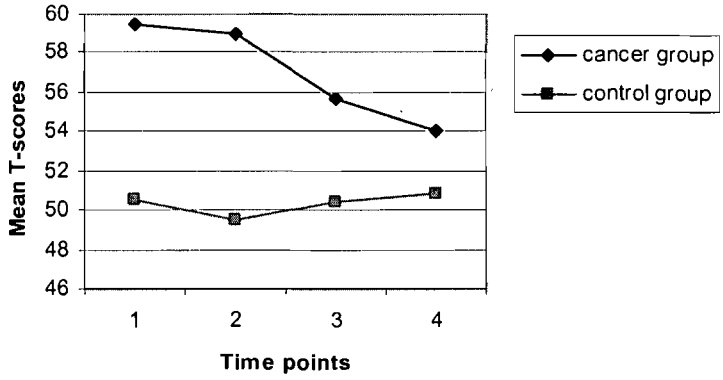

Figure 6-A. Anxiety scores for the cross-sectional sample per group through time

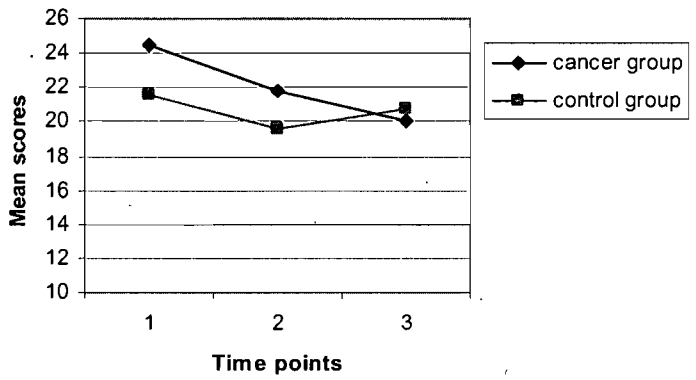

Figure 7-A. PSS scores for the cross-sectional sample per group through time

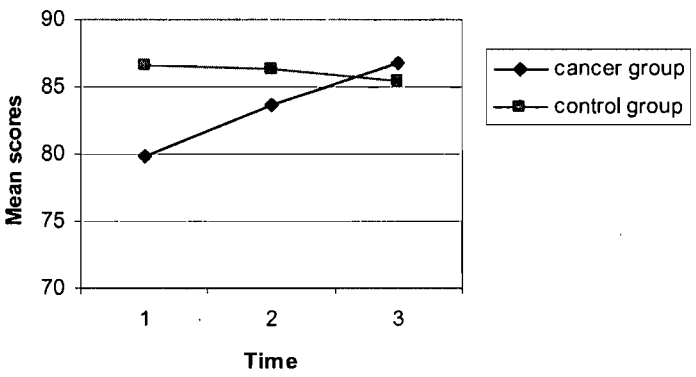

Figure 8-A. FACT-G: (quality of life) scores for the cross-sectional sample per group through time

SECTION 4: GENERAL CONCLUSION

General Summary

The combined objectives of the present studies were: to explore the cancer related symptoms of PTSD and distress (specifically symptoms of depression and anxiety); to determine the frequency of PTSD symptoms in young male cancer patients; to assess the evolution of PTSD symptoms in the first year following a cancer diagnosis as they relate to risk factors predictive of PTSD symptoms; and to examine the coping and posttraumatic growth experiences of survivors.

The susceptibility to PTSD symptoms in patients with cancer is supported by the results of this research project. From the results of the qualitative study (Study 1), we observed that the initial reaction to the diagnosis of cancer is one of anxiety, the reaction during the treatment phase is one of depressed affect and the reaction in the post-treatment phase is a combination of PTSD symptoms and integration of the experience through cognitive processing. In a paper about the cognitive model of posttraumatic stress disorder (Ehlers & Clark, 2000) the authors mention that the possibility of loss is associated with anxiety, whereas the certainty of loss is associated with depression. In study 1, anxiety was closely tied to the period following diagnosis and depression was frequent during the treatment phase. In the qualitative study, the intrusive thoughts reported by survivors at diagnosis and treatment strongly resembled anxious worries about future threats while intrusions reflecting past experience (the impression of seeing cancer everywhere, thinking about cancer when they did not mean to) only appeared post-treatment. The results presented in this study illustrate the many anxious worries about the future that patients experience: the fear of death, the unknown nature of treatments, possible

complications and side-effects. These anxious worries resemble the intrusive symptoms of PTSD, but they are related to preparing oneself to respond to a future threat rather than the recurrent thoughts about a past trauma, as is more typical of PTSD. As described elsewhere (Mundy & Baum, 2004), the worries in patients diagnosed with a life-threatening illness may be more future-oriented than focused on the past. In the present study, it is only in the long-term survival phase that intrusions made their appearance, thus earlier observations may be more characteristic of anxiety. More survivors reported the presence of PTSD symptoms, such as high intrusions, avoidance, hypervigilance and emotional numbing in the post-treatment phase. Still, many survivors reported a general good adjustment and posttraumatic growth.

The quantitative study (Study 2) revealed significantly greater PTSD symptom severity in cancer patients as compared to controls at every time point on the PCL-C except at time one, and had higher scores on the IES at times 2 and 4. The effect remained stable when PTSD symptom severity at time 1 was controlled. In contradistinction, scores of depression and anxiety, which were initially elevated for the cancer patients, decreased over time, while remaining consistently at low levels for the controls. Other indicators of well-being failed to identify a difference between groups. There was no group difference in perceived stress or quality of life.

In terms of the evolution of cancer-related PTSD symptoms, both studies pointed towards an initially low level of PTSD with either stability or an increase over time. There was, however, a significant decrease in symptoms for the control group participants. This finding contradicts previous longitudinal studies that report highest

levels of cancer-related PTSD symptoms at the time of diagnosis followed by a gradual decline over time (Kangas et al. 2005a, 2005 b, 2005c, 2005d; Manuel et al. 1987).

Lazarus and Folkman's (1984) Transactional Coping Theory views appraisal as preceding coping and involves both primary and secondary appraisal processes. In primary appraisals, individuals assess events as threats, losses, challenges, benefits, or as irrelevant. Challenges are defined as opportunities for improvement. However, in the case of traumatic stress, it is less likely that events will be defined as opportunities for improvement, with the exception perhaps of being faced with a chronic illness such as cancer (Mundy & Baum, 2004). These positive reappraisals of the cancer diagnosis from being a threat to a challenge may be at the root of posttraumatic growth.

It is possible that the search for meaning, through cognitive processing of the experience, allows acceptance (Little et al., 2002). The perceived threat motivates a series of behavioural and cognitive responses that reduce the threat and distress in the short-term. Avoidance may be adaptive in the face of immediate trauma (Ehlers & Clark, 2000), but has the consequences of preventing cognitive change and therefore maintaining the disorder in the long-term (Ehlers & Clark, 2000). Efforts not to think about the traumatic event prevent individuals from elaborating the trauma memory and linking their experience with its context in time, space, previous and subsequent information and other autobiographical memories (Brennan, 2001; Foa et al., 1989; McMillen et al., 2000; Suls & Fletcher, 1985). They also prevent changes in appraisals.

The presence of growth does not necessarily signal an end to pain or distress, and usually it is not accompanied by a perspective that views the crisis, loss, or trauma itself as desirable. Many persons facing devastating tragedies do experience growth arising

from their struggles, but only the growth is desirable, not the tragedies themselves (Tedeschi & Calhoun, 2004). Both positive and negative outcomes can occur, either simultaneously or sequentially, in the same individual. Virtually every cancer patient who reports posttraumatic growth also reports some distress. Survivors must relinquish some pre-illness goals and basic assumptions and attempt to build new ones at the same time. Survivors re-construct their identities in ways that accommodate the experience and its sequelae, that is, they resume a version of their former lives but they incorporate aspects of their illness experience into their lives (Little et al. 2002).

The coping processes taking place also influence the cognitive integration of trauma and the extent of posttraumatic growth. For example, the opportunity to talk about the experience of cancer and the presence of social support may be additionally beneficial to cognitive processing and may help through the provision of alternate schemas (Tedeschi & Calhoun, 2004). In contrast, individuals who are remarkable in hardiness, possess a high sense of coherence and who are highly resilient, may not be challenged sufficiently by the traumatic event to enter a process of revaluation of existing schemas (Tedeschi & Calhoun, 2004). In our study, some survivors mentioned coping by staying active which might reflect an attempt to preserve assumptions about the self. In contrast, personality characteristics such as optimism, extraversion and openness to experiences, which allows for a flexible re-evaluation of assumptions, may make posttraumatic growth more likely (Tedeschi & Calhoun, 2004).

The present research has numerous strengths. First, the use of triangulation, through a combination of investigative methods (qualitative analysis, theoretical integration and quantitative analysis) allowed for a retrospective and prospective account of cancer

related-PTSD symptoms. Additionally, the presence of a qualified interviewer in both study 1 and study 2, ensured uniformity in test-taking conditions within each study. The qualitative information allowed for an initial exploration of the singular expression of PTSD symptoms in cancer patients. Prospective data collection helped reduce recall bias often present in retrospective measures and the inclusion of more than one questionnaire on PTSD allowed a better coverage of the construct. Furthermore, the use of complimentary statistical analyses (correlations, linear regressions, repeated measure ANOVAs, ANCOVAs, chi-squares and logistic regressions) strengthened the conclusions of this study. Combined altogether, this rich data provides a novel and integrated understanding of the development of posttraumatic reactions from diagnosis to long-term recovery.

Limitations

One of the limitations of the study is the voluntary and non-random recruitment of the participants. The results of these studies may not generalize to other cancer populations of young males, to female cancer patients, or to older patients. There was a low variability in age, marital status and education; sample may not be representative of the population. The sample recruited in this study was very homogeneous. The men in our study were all Caucasian; the majority was employed full-time and earned a higher income than most Canadians.

In the qualitative study, it is possible that men who were most concerned by fertility issues were those who accepted to participate in the study. Generalizations are restricted by the large amount of time elapsed between post-treatment and data collection. Survivors resume to a version of their former lives within the context of changed

identities and new insight (Little et al., 2002). Survivors integrate the cancer experience within their self-concept and also reconstruct their self-concept. As survival is clearly the main goal, survivors may be expected to experience gratitude, acceptance and satisfaction at the thought of being alive (Little et al., 2002). As such, current autobiographical memories of the cancer trajectory may be biased by a reconstructed identity. The longitudinal component of the project, as presented in study 2, addressed this issue by following patients prospectively.

The conclusions of study 2 are limited by our sample size. Failure to demonstrate a difference between groups or between time points may be due to lack of statistical power. Moreover, patients dropping out of the study limited the power of longitudinal analyses by reducing the sample size even further. Data replacement cannot be performed to replace entire time points for those who missed an assessment. When reporting longitudinal analyses, only complete cases can be used, or it is impossible to make an argument for the effect of time. Missing data was problematic as analyses need to be done on the same individuals through time. Another limitation of study 2 pertains to the instruments used that may limit the validity of conclusions. As was mentioned the IES does not measure whether symptoms of intrusions and avoidance are associated with impaired functioning and distress following the stressful events. However, the use of the PCL-C as a second instrument to assess PTSD symptoms did take distress into account. In study 2, incidence rates of cases of moderate to severe PTSD symptoms were consistently lower on the PCL-C than on the IES. It could possibly be that a certain proportion of individuals score high on the IES but not on the PCL-C as they are experiencing some cognitive symptoms but are not distressed about them. These

individuals may have symptoms but interpret or reframe them into something that they can cope with.

Directions for future research

As frequency of PTSD symptoms in our sample was similar or modestly lower than other studies, and given the great variability in reported prevalence in the literature (Kangas et al., 2002) meta-analyses are needed to make further conclusions. Future studies should also investigate closely the possible gender difference in trajectory of PTSD symptoms. Longitudinal analyses did not reveal a trend towards a decline in PTSD symptoms in this male sample, while earlier studies of PTSD in female or mixed gender samples reported a rapid decline in symptoms in the months following diagnosis. Future research is needed to ascertain whether there is a possible effect of gender on the course of PTSD symptoms.

Future research could attempt to measure stressful life events at the time of diagnosis. This would allow controlling differences between groups on the basis of recent life stress. Future research could also attempt to measure personality characteristics associated with PTSD which might account for individual differences in the development of PTSD.

As other authors have noted, the relationship between distress and posttraumatic growth is unclear (Tedeschi & Calhoun, 2004). Some researchers have found a positive association between perceived benefits of cancer and adjustment (Taylor, Lichtman, & Woods, 1984), whereas other researchers have not (Andrykowski et al., 1993; Fromm, Andrykowski, & Hunt, 1996). This association needs to be clarified.

We did not measure coping styles and their impact in a prospective and longitudinal manner. Some coping styles, like emotional social support, an active and engaged

approach to cancer, and optimism lead to better adjustment in front of uncontrollable, life-threatening events such as cancer (Carver et al., 1993; Cuttrona & Russell, 1990; Epping-Jordan et al., 1999). Likewise, some strategies used to control the impact of the event may be maladaptive. Thought suppression through attempts at pushing thoughts about the trauma out of their minds will increase the frequency of unwanted intrusive recollection (Ehlers & Clark, 2000). Others may try not to think about the event by keeping their mind constantly busy, taking drugs, or drinking alcohol (Ehlers & Clark, 2000). Future research should endeavour to measure coping styles and their impact on cancer-related PTSD symptoms. A study of the expression of cancer-related PTSD symptoms, in the form of clinical interviews, case studies or qualitative studies, would clarify the amount of distress that is associated with these symptoms.

Future prospective research should include follow-ups longer than one year to document the course of PTSD and distress, and to document the persistence of posttraumatic growth and new schemas. It is possible that posttraumatic growth may be limited to the early months or years following completion of cancer treatment. This information has not yet been documented in the literature.

Conclusion

There were only a minority of cancer survivors who experienced heightened levels of cancer-related PTSD symptoms. The cancer experience is a stressor on an acute and chronic basis, disruptions of normal functioning are present from diagnosis and may persist over the long-term remission phase. As a return to health gradually takes place, depression and anxiety symptoms wane, but for some survivors PTSD symptoms remain stable. Whether these symptoms are associated with decreased functioning or are an

expression of cognitive integration of the experience is to be investigated. This project began to describe how initial appraisals of the cancer diagnosis can impact outcomes in PTSD symptoms. Some patients reappraised the diagnosis as a challenge and as something that was manageable, this allowed for a cognitive processing of the threat information that was conducive to posttraumatic growth. Health care professionals would benefit from an understanding of the factors and timeline associated with patient's distress; this would allow them to adapt their practice and care in order to provide help to those most in need of it.

Since the period following the diagnosis is characterized by shock, distress and anxiety, it would be appropriate that the large amount of information that is presented to patients be repeated several times by the many professionals who encounter the patient. This may alleviate some of the stress associated with the unfamiliar processes that will order their lives for the months ahead, when the initial diagnosis is reappraised as something manageable; a challenge over which one can exercise some control, as a result, patients may be less likely to experience PTSD symptoms.

The results of our study suggest that patients are under a significant amount of emotional duress especially during the treatment phase. Clinical interventions might be an important source of support for patients but perhaps not in this stage. The findings from this research support the argument for late psychosocial interventions. In an intervention study, researchers found that the group who had received a late intervention (8 months post-diagnosis) showed greater declines in intrusive thoughts at 12 months post-diagnosis than those who received an early intervention (4 months post-diagnosis) (Edgar et al. 1992). This effect may be related to the larger presence of denial and

avoidance in the early period following diagnosis, while the need for cognitive processing may arise later, once the acute treatment phase is finished.

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APPENDIX 1- CO-AUTHORS AGREEMENT